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Transformation through adaptation: A grounded theory of the patient experience of Alcohol-Related Brain Damage

Heather Jayne Simpson
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Connor and Graham – it's all about you now boys!

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Whole Thesis Abstract

Background: Alcohol Related Brain Damage (ARBD) is an umbrella term used to describe the range of effects that long-term consumption of alcohol can have on the structure and function of the brain. Despite the increasing prevalence of ARBD, there is a lack of research in this area, and as a result, there are no current guidelines and few services available for the treatment of this condition. There is therefore a need to increase the evidence base in this area, which will assist in the understanding, and ultimately treatment, of ARBD.

Aims: This thesis consists of two parts. The first is a systematic review journal article which asks the question: "What is the impact of alcohol-abuse on memory function within the first three weeks of alcohol withdrawal?" The second part is a qualitative research project which aims to develop a grounded theory regarding the patient experience of ARBD, identifying and highlighting themes and concepts that are central to the experience.

Methods: For the systematic review, four databases were searched. Studies that were included in the review had to have participants with alcohol-dependence; abstinence of less than or equal to three weeks; and to have undergone some form of neuropsychological assessment of memory function. Data from 15 articles were extracted and assessed for quality. For the qualitative study, participants (n=10) were interviewed regarding their experiences of ARBD and the data was then analysed using grounded theory methodology.

Results: The results of the systematic review were somewhat ambiguous with some studies reporting impairments in verbal and visual memory, while other studies found no impairments. Episodic memory deficits were present in all studies reviewed. The results of

the qualitative study propose a tentative model which describes "transformation through adaptation". This model hypothesises that successful negotiation of the journey through ARBD hinges on the adaptations that need to be made in order to progress towards transformation. The model is understood in the framework of a number of phases, "*Being diagnosed with ARBD,* "*Focusing on abstinence*", "*Taking ownership of life with ARBD*" and "*Creating a valuable life*", all of which exist within a framework of being supported by specialist services.

Conclusions and implications: The systematic review demonstrated some support for deficits in visual and episodic memory within the first three weeks of abstinence, while it appeared that verbal memory was relatively preserved. The heterogeneity of the studies, coupled with the methodological variability, meant that all conclusions need to be considered as tentative, and be interpreted with caution. The main difficulties with interpretation were to do with the confounding factors often found within this client group. The results reinforce the concept of tailored treatment programmes for individuals due to the large variability of the effect of alcohol (and other factors). The qualitative study proposes a model that shows how adaptation appears to play a key role in the successful negotiation of a diagnosis of ARBD. The study describes a series of categories that can be used as a framework to identify and support the changes that are necessary for recovery and reintegration. The value in this study is that the results are directly attributable to individuals who have been diagnosed, and are now successfully living, with ARBD.

Systematic Review

The neuropsychological impact of alcohol on alcohol-dependent patients within three weeks of withdrawal: A systematic review of observational studies

Heather Jayne Simpson*, University of Edinburgh, NHS Lothian, Edinburgh, UK

Ethel Quayle, University of Edinburgh, Edinburgh, UK

Suzanne O'Rourke, University of Edinburgh, Edinburgh, UK

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**University of Edinburgh, School of Health in Social Science, Medical School, Teviot Place, Edinburgh, EH8 9AG*
Tel: (+44) 131 651 3972
Email: heather.simpson@nhslothian.scot.nhs.uk

The neuropsychological impact of alcohol on alcohol-dependent patients within three weeks of withdrawal: A systematic review of observational studies[1]

Background: Cognitive assessments carried out within three weeks of abstinence will provide information about the functioning of the patient during the detoxification period. If patients do not have the cognitive capacity to participate in a standardised treatment, they are likely to relapse; reinforcing the 'revolving-door' cycle that is often seen in alcohol services.

Methods: Studies that were found as a result of a systematic search included participants with alcohol-dependence; abstinence of less than or equal to three weeks; and to have undergone some form of neuropsychological assessment of memory function. Data from 15 articles were extracted and assessed for quality.

Results: The results of the systematic review were somewhat ambiguous, with some studies reporting impairments in verbal and visual memory, while other studies found no impairments. Episodic memory deficits were present in all studies reviewed.

Conclusions: The systematic review demonstrated some support for deficits in visual and episodic memory within the first three weeks of abstinence, while it appeared that verbal memory was relatively preserved. The heterogeneity of the studies, coupled with the methodological variability, meant that all conclusions need to be considered as tentative, and be interpreted with caution. Difficulties with interpretation of these results and suggestions for future research are discussed.

Word count: 203

KEY WORDS: ***memory, alcohol-dependent, abstinence, cognitive***

[1] Written up in the style of Drug and Alcohol Dependence – full author guidelines are provided in Appendix 6

Introduction[2]

Alcohol-related brain damage (ARBD) is an umbrella term which is used to describe the variety of cognitive impairments which develop as a consequence of chronic alcohol abuse and associated nutritional deficiencies (Royal College of Psychiatrists, 2014). The profile of ARBD has been raised in recent years, demonstrated by the expanding field of research (e.g. Wilson et al., 2012; Svanberg &Evans, 2013) and the development of tailored services in the United Kingdom to treat patients with this condition. While three quarters of people with ARBD are predicted to make some level of recovery (Victor et al., 1971), the most effective way to prevent ARBD would be to help support people to abstinence before the cognitive impact of alcohol became problematic.

The neuropsychological domains affected by alcohol abuse are reported to be mainly executive functioning and memory (e.g. Nixon, 1995; Parsons, 1998; Weinstein & Shaffer, 1993). While these alcohol-related impairments can be severe, some may ameliorate or even resolve within a few weeks or months (e.g. van Eijk et al., 2013; Loeber et al., 2010); however, complete or partial recovery of cognitive function could take a number of years (e.g. Fein et al., 2006; Crews et al. 2005).

There is no doubt that continued drinking is linked to sustained and worsening cognitive difficulties (Royal College of Psychiatrists, 2014). As such, the National Institute for Health and Clinical Excellence (NICE; 2011) in the United Kingdom advise abstinence as the most appropriate treatment approach for patients with alcohol-dependence. NICE (2011) also recommend treatments such as cognitive behavioural therapy and couples therapy that require behaviour change and the development of skills to prevent relapse. These types of treatment require effective use of cognitive functions such as memory (to retain information given and to learn new behavioural processes) and executive functioning (such as decision-

[2] Numbering required for publication has been omitted for the purposes of consistency within this thesis document

making) and those with alcohol-related cognitive deficits may struggle to engage (e.g. Carroll et al., 2011).

The National Institute for Health and Clinical Excellence (2011) recommends that cognitive functioning is assessed as part of a comprehensive assessment for adults when referred to specialist alcohol services, as cognitive impairment is present in most people who misuse alcohol presenting for detoxification treatment; however there are some difficulties with this approach. Cognitive functioning is often impaired at the commencement of detoxification due to the highly toxic effects of alcohol (Oscar-Berman et al., 1997) and can initially give a false picture of cognitive functioning, as an improvement in cognitive functioning is often seen within a few weeks of abstinence (Bates et al., 2002). As a result, cognitive functioning is typically assessed after 3-6 weeks of abstinence (Ryan & Butters, 1986), although there are obstacles and difficulties with achieving this level of abstinence for many patients with severe alcohol dependence. While cognitive assessment carried out within the initial detoxification period may not provide an accurate long-term picture of cognitive functioning, it is likely to provide crucial information about the functioning of the patient during the detoxification period and their consequent ability to participate in treatment.

It is this ability to participate in, and adhere to treatment that is important to assess in the early days of detoxification. The treatment as recommended by NICE (2011) is likely, in most cases, to commence at the end of a detoxification/withdrawal process, which often lasts no more than 5-10 days. The result is that patients are still potentially in the "acute" phase of cognitive impairment at the point that treatment begins. Cognitive assessments carried out within the initial detoxification period (i.e. within three weeks) may not provide an accurate long-term picture of cognitive functioning (which is why they are often not conducted at this time-point in clinical practice); they will, however provide information about the functioning

of the patient during the detoxification period and inform on their consequent ability to participate in treatment. If patients do not have the cognitive capacity to participate in a standardised treatment, they are likely to relapse; reinforcing the 'revolving-door' cycle that is often seen in alcohol services. In order to break this cycle, it is important to determine what cognitive deficits patients are likely to experience during this time and make adjustments within the treatment process to support these difficulties until they improve.

Executive functioning and memory are often cited as the main areas of impairment as a result of chronic alcohol-abuse (e.g. Stavro et al., 2014; Lezak et al., 2004; Bates et al., 1997). While the literature on executive functioning has been well reviewed (e.g. Moselhy et al., 2001; Macdonald, 2012 – unpublished thesis), the literature on memory remains less clear. In fact, the current evidence for memory deficits in alcohol-dependent patients (ADP) is relatively ambiguous with many studies reporting conflicting results. Many studies also cite memory deficits as a result of alcohol-abuse without specifying what areas of memory are affected (e.g. Royal College of Psychiatrist, 2014). Lezak et al. (2004) summarises a number of studies which suggest that verbal memory is less affected than visual memory as a result of alcohol abuse (e.g. Bowden, 1988; de Renzi et al., 1984; Kapur & Butters, 1977; Ryan & Butters, 1986; Shelton et al., 1984). Other studies, however, have found deficits in both verbal and visual memory (e.g. Nixon et al., 1987). Evidence has also been found to suggest episodic memory impairments (Beatty et al., 1995; Couvilliers et al., 2005; Fama et al., 2004; Nixon et al., 1998).

Stavro et al. (2013) conducted a meta-analysis of 62 studies and reported on evidence that suggested both verbal and visual memory deficits as a result of alcohol-abuse. They examined a range of different stages of abstinence (short-, intermediate- and long-term), with the short-term category ranging from 0-31 days abstinence; however, they did not differentiate within this category. In other words, abstinence duration of 0 days was

compared with abstinence of 31days; however significant recovery can occur within the first three weeks of abstinence (e.g. Brandt, Butters & Ryan, 1983; van Eijk et al., 2013) which provides reason to believe that the impairments exhibited at these two time-points would differ in some way. Due to the lack of information about memory function in the very early stages of abstinence, and the impact that this could have on treatment efficacy, it was felt that a review which looked specifically at the three-week period after withdrawal would be essential.

The aim of this paper is to review the evidence of the impact of chronic alcohol-abuse on memory function in ADP within three weeks of abstinence. The objective is to clarify the areas of memory that are impaired in alcohol-dependence at the point at which treatment would commence.

Methods

Evidence for the effects of chronic alcohol-abuse on memory functioning in ADP within three weeks of abstinence was assessed by conducting a systematic review of published research evidence. The review adhered to published guidance for undertaking reviews in health care (Centre for Reviews and Dissemination, 2009). A search of the Cochrane Database of Abstracts of Reviews of Effects (DARE) and PROSPERO were carried out to identify any existing or planned systematic reviews. None were found.

Search strategy

Studies for review were identified by searching major electronic databases including MEDLINE (from 1946), EMBASE (from 1974), PsycINFO (from 1806) [3]and SCOPUS

[3] EMBASE, MEDLINE and PsycINFO databases were all accessed using the OVID web-based searching software

(from 1960). No limits were placed on dates in order to ensure as broad a search result as possible. Searches were carried out by the main author (HJS) and took place on 14/09/2014. The following search terms were applied in combination with the Boolean operator 'AND':

- Alcohol*[4]
- Withdraw* OR detox* OR early abstinence OR sober
- Cognit* OR memory OR attention OR executive function* OR decision making OR neuropsych*[5]

Where possible, limits were placed on the searches to exclude animal studies and to include only English-language journal articles. An example of the search run in SCOPUS can be seen in Appendix 1.

For completeness, and to increase the sensitivity of the search, reference lists were hand-searched for relevant articles and a citation search was also carried out on the articles selected for review. Two journals (Alcoholism: Clinical and Experimental Research and Alcohol and Alcoholism) were also hand-searched over a 5-year period (September 2009 – September 2014) to identify any potentially relevant studies. Two main authors in the field were also contacted seeking further relevant papers.

Study selection

The main author conducted the electronic searches and screened first by title, then abstract and finally by a reading of the full-text articles. Studies that did not meet inclusion criteria were excluded, with reasons reported at the full-text level (see Table 2). When reviewing at abstract level, if there was any doubt regarding the eligibility of the article, it was progressed

[4] The term "ethanol" was not used as scoping searches revealed that this term was predominantly used in animal studies.

[5] The truncation [*] was utilised in order to increase search sensitivity.

to the full-text review stage. A random selection of half of the full texts was screened independently by another clinician.

Inclusion and exclusion criteria

As the aim of this review was to examine and summarise the current evidence regarding the neuropsychological impact of alcohol on memory within three weeks of abstinence, it was necessary to take a broad approach to the inclusion and exclusion criteria. The relevance of each study for inclusion was assessed according to the criteria in Table 1.

Table 1. Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
• Adult population (over 18 years of age) • Participant with alcohol dependency • Abstinence within a 3 week period • Involved the use of a measure to assess neuropsychological outcomes relating to memory • Included a 'healthy' control group • English language publication • Full-text version available online or via the British Library	• Animal studies • Dissertation and thesis abstracts • Tissue studies • Reviews and case studies • Theoretical papers

While it is understood that including only English publications increases the possibility of bias, lack of resources available for translation precluded the inclusion of other languages.

Data extraction

Descriptive data were extracted for each included study and recorded in separate tables according to the type of memory assessed. The details extracted were: study, year and

country; neuropsychological assessment measure; type of memory assessed; number of alcohol-dependent participants (% male), mean age and range; number of healthy controls (% male), mean age and range; factors that groups were matched on; education; length of alcohol-dependence; length of abstinence; and a summary of key findings. Only results that were relevant to the present review question were reported.

Quality assessment

Assessment of quality is an important step in reviewing a body of evidence due to the possibility of bias being introduced as a result of methodological and reporting weaknesses (Centre for Reviews and Dissemination, 2009). It is accepted that there is no one single approach to assessing quality that is appropriate for all types of systematic reviews (Centre for Reviews and Dissemination, 2009), therefore a checklist was created, based on the needs and aims of this review. The criteria were developed based on the advice provided by the Centre for Reviews and Dissemination (2009), and influenced by both SIGN 50: A guideline developer's handbook (2008) and Vandenbroucke et al.'s paper on Strengthening the Reporting of Observational Studies in Epidemiology (STROBE; 2007).

Summary of measures

Studies were rated using thirteen quality criteria across six different domains: research question; selection of subjects; assessment and measures; analysis and results; discussion; and overall quality (see Appendix 2 for quality assessment form). Ratings were assigned to each criterion and were scored as follows: well covered (2 points); adequately addressed (1 point); poorly addressed (0 points); not addressed (0 points); not reported (0 points); not applicable (0 points), giving a total score out of 26. The numerical scores were calculated for each study and converted into percentages for the domains and to provide an overall score.

Eight of the studies were also reviewed independently by a psychology colleague. Inter-rater reliability was calculated on total scores: exact and adjacent agreement was 87.5%, with three papers being rated the same; four differing by one point; and one differing by two points. Where ratings on items differed, these were discussed, and a consensus rating agreed.

Data synthesis

Due to the heterogeneous nature of the studies' designs, measures and outcomes, a meta-analysis was not appropriate within this review. Findings were synthesised using a narrative approach.

Results

Search results

The search strategy initially identified a total of 5774 publications from OVID, reducing to 4200 after removing duplicates; 4009 after limiting to journal articles; and to 3638 after limiting to articles printed in English. A further 3442 titles were identified from SCOPUS; reducing to 2078 after limiting to journal articles; and to 1891 after limiting to articles printed in English. A total of 5529 publications were exported to EndNote, where a further 2019 duplicates were removed[6], leaving a total of 3510 to review.

The titles of these 3510 articles were screened for eligibility using the inclusion criteria, resulting in the exclusion of a further 3227. The remaining 283 publications were then screened by abstract, leaving 82 articles to review. Every attempt was made to access all 82 full-text articles for review by using online journal subscriptions, and where necessary, by

[6] These duplicates were not removed during the automated process described above as they differed slightly in spelling or format (e.g. full name versus initial) and therefore had to be manually removed in EndNote

contacting the authors or by making a request through the British Library. Two articles could not be obtained. After full-text review, 11 articles were selected for methodological review and appraisal. Table 2 provides an overview of reasons for exclusion at this stage.

Table 2. Reasons for exclusion at full-text screening

Number of studies excluded	Reasons for exclusion n=70
30	Abstinent for over 3 weeks at the time of assessment.
4	Length of abstinence not stated/unspecific
11	No measurement of memory function
6	No normal control group
1	Study not relevant
1	No withdrawal/abstinence
2	Relevant results not available
4	Conference abstracts
1	Foreign language paper
4	Studies looking at working memory
1	Letter to the Editor
2	Same population and measures as other included papers
2	Full-text was not accessible

An additional four studies were added from hand (1) and reference (3) searching, resulting in a total of 15 papers selected for methodological review and appraisal. A flowchart based on the PRISMA statement (Moher et al., 2009) showing an overview of the process can be seen in Figure 1.

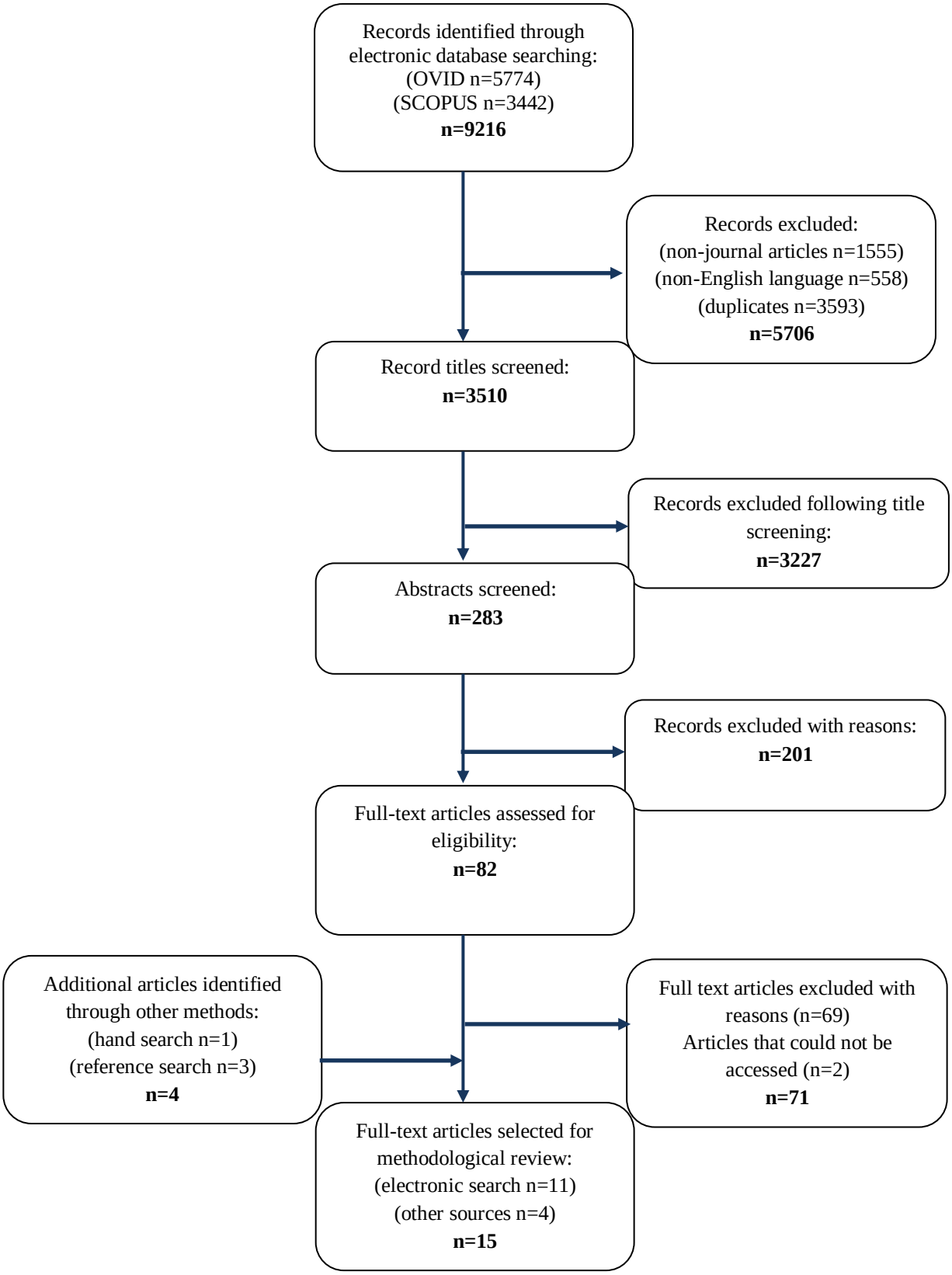

Figure 1: Flow chart of article selection (adapted from Moher et al., 2009)

Quality ratings

The results of the quality review of the studies can be seen in Table 4. The variable nature of the studies in terms of measures, study design and sample size, make it difficult to compare the quality of these studies directly. However, the quality review process provides additional clarity on methodological strengths and weaknesses. These issues are discussed in greater detail below.

Table 3. Quality review ratings

Study	Research question (out of 2)	Selection of subjects (out of 6)	Assessment of measures (out of 4)	Analysis and results (out of 6)	Discussion (out of 8)	Overall score (out of 26)
Emmerson et al. (1988)	1	4	1	1	5	12
Taylor, McGown & Anson (1997)	2	4	2	1	4	13
Mann et al. (1999)	1	4	4	1	2	12
Fitzgerald & Shifley-Grove (1999)	1	5	1	1	5	13
Demir et al. (2002)	1	3	1	1	7	13
Hildebrandt et al. (2004)	2	3	1	1	3	10
Moriyama et al. (2006)	0	4	1	0	8	13
Pitel et al. (2007a)	1	3	1	1	5	12
Loeber et al. (2009)	2	6	3	1	6	18
Le Berre et al. (2010)	2	5	2	1	3	13
Daig et al. (2010)	2	5	2	2	5	16
Daig et al. (2012)	2	4	1	2	4	13
Le Berre et al. (2012)	1	5	2	1	8	17
Wollenweber et al. (2014)	0	3	1	1	3	8
Ritz et al. (2014)	2	4	3	1	7	17

Six of the studies scored in the 50% bracket, three in the 40% bracket and two in the 30% bracket. Only four studies achieved a score over 60%. It is important to point out, however that the studies were not methodologically weak across all domains, but rather demonstrated weaknesses in particular areas. How the papers were rated across the different domains is discussed in more detail below:

Research question

Seven of the 15 studies scored highly within this domain (Taylor, McGown & Anson, 1997; Hildebrandt et al., 2004; Loeber et al., 2009; Daig et al., 2010; Le Berre et al., 2010; Daig et al., 2012; Ritz et al., 2014) by explicitly providing background information, a hypothesis or precise study question, and information regarding the proposed study. Five of the studies (Emmerson et al., 1988; Fitzgerald & Shifley-Grove, 1999; Mann et al., 1999; Pitel et al., 2007a; Le Berre et al., 2012) scored 50% indicating that some of the issues were addressed, but not all; and three of the studies (Demir et al., 2002; Moriyama et al., 2006; Wollenweber et al., 2014) scored 0% as it was felt that they did not adequately address the research question.

Selection of subjects

All studies achieved a score above 50% in this domain, with four of the papers achieving a score of over 80% (Fitzgerald & Shifley-Grove, 1999; Loeber et al., 2009; Le Berre et al., 2010; Le Berre et al., 2012). The main methodological weaknesses present in the lower scored papers were a lack of specificity about where the control group was selected from and a lack of detail about the exclusion criteria applied (or exclusion criteria were different for the two groups).

Assessment and measures

The quality of assessment of measures was low (50% or below) across all but three of the studies (Mann et al., 1999; Loeber et al., 2009; Ritz et al., 2014). The reason that most of the studies scored poorly in this area was due to the lack of reference to the reliability and validity of the neuropsychological measures used. While the outcomes were mostly well described, less attention was given to the potential confounders.

Analysis and results

Most papers were consistently weak across this domain, with no studies scoring over 33%. No papers reported on power or confidence intervals. Only two reported on effect sizes (Daig et al., 2010; Daig et al., 2012). The statistical analysis methods were appropriately reported and justified, with some papers providing significantly more information than others.

Discussion

Four papers scored below 40% in this category (Mann et al., 1999; Hildebrandt et al., 2004; Le Berre et al., 2010; Wollenweber et al., 2014). Two papers scored 50% (Taylor, McGown & Anson, 1997; Daig et al., 2012), with the remaining papers scoring over 60%. It was felt that all papers reported their results with reference to the study objectives, and in general, interpretation of the results was cautious and considerate of objectives. The areas of weakness in this domain were predominantly related to reporting on limitations and generalisability.

Overview of reviewed studies

Fifteen studies were undertaken in five countries (US (2), Australia (1), Germany (6), Turkey (1), Japan (1) and France (4)) between 1988 and 2014, and met criteria for inclusion in this systematic review[7]. These papers included a total of 438 ADP (of which 12 participants were diagnosed with Korsakoff's Syndrome) and 368 healthy control participants; a summary of which can be seen in Table 4. The areas of memory examined were verbal, visual, episodic, autobiographical, metamemory and motor memory. Measures of working memory were not included in this review as it is generally understood that working memory is considered to be a measure of executive functioning (Baddeley, 2012) rather than memory per se. Many of the studies incorporated measures of memory as part of a larger study incorporating other neuropsychological measures; only the memory measures will be reviewed here.

Due to the lack of studies available examining autobiographical memory (n=1), metamemory (n=2) and motor-memory (n=), a decision was made to exclude these results from the review, leaving a total of 14 studies which focused on visual, verbal and episodic memory.

A variety of measures were used to assess the areas of memory examined within this review. Verbal memory was assessed using the Verbal Learning and Memory Test (VLMT), the Auditory Verbal Learning Test (AVLT), the Memory Screening Test (MST), and the Wechsler Memory Scale (WMS); visual memory was assessed using the Benton Visual Retention Test (BVRT), the Figure Position Test (FPT), the Rey-Osterrieth Complex Figure Test (R-OCFT), the MST and the WMS; and episodic memory was assessed using the Free and Cued Selective Reminding Test (FCSRT) and the Spondee test. A summary of these measures can be found in Appendix 3.

[7] All included studies are marked with * in the reference section

Study range and characteristics

Table 4. Study characteristics

Study; year; country	Neuro-psychological assessment measure	Type of memory	Number of alcohol-dependent participants (%male); mean age (SD); range	Number of healthy controls (%male); mean age (SD); range	Matched for:	Education (years) ADP/CG	Length of alcohol dependence (years); range	Length of abstinence (days)	Summary of key findings
Emmerson et al. (1988); US	BVRT	Visual	20 (100%); 35.1 (*not reported*)	20 (100%); 32.6 (*not reported*)	Age	12.8 / 14.9	13.2 (4.1)	11.6 (7.2)	ADP performed worse than CG on BVRT (number correct and total errors)
Taylor, McGown & Anson (1997); Australia	MST	Verbal Visual	16 (75%); 36.5 (7.0) 24-48	16 (68.7%); 37.8 (7.3); 24-51	Age and years of education	10.9 (2.4) / 11.8 (1.5)	14.1 (7.9); 1-29	4.8 (2.1)	*Verbal memory:* No significant differences were found for word and sentence recall *Visual memory:* Significant differences were found in the mean number of errors made by ADP compared to CG on figure recall and the total number of errors
Mann et al. (1999); Germany	Logical memory subtest of the WMS AVLT BVRT	Verbal Visual	49 (100%); 41.7 (9.0); 24-60	49 (100%); 41.8 (8.9); 24-60	Age, education and marital status	Equivalent (9-13)	11.4 (5.5); 2-26	17.8 (29.4)	*Verbal memory:* ADP performed significantly worse than CG on immediate recall, but were equivalent on delayed recall *Visual memory:* ADP and CG performed equivalently on BVRT
Demir et al.	WMS	Verbal	24 (100%);	6 (100%);	Age and	10.3 (3.2) /	18.5 (9.3)	15-21	*Verbal Memory:* No

(2002); Turkey		Visual	42.6 (9.8); 27-65	40.00 (9.13); 31-56	education	11.0 (1.67)			significant differences were found between ADP and CG *Visual memory:* ADP performed significantly worse than CG on visual reproduction I, II and visual memory span
Hildebrandt et al. (2004); Germany	CVLT (German version)	Verbal	24 (*not reported*); 52.0 (7.0) 12 Korsakoff (*not reported*); 56 (6)	40 (*not reported*); 51.0 (9.0)	Age, intelligence (pre-morbid and general) and simple RTs	Matched on general intelligence	17.0 (9.0); Korsakoff 26.0 (6.0)	14-21	ADP and CG showed a similar learning and recall ability
Moriyama et al. (2006); Japan	FPT	Visual	39 (100%) 50.0 (5.7)	15 (100%); 50.4 (5.5)	Age and education	12.2 (2.9) / 12.8 (3.1)	13.4 (8.3)	13.4 (2.9)	ADP performed worse than CG
Pitel et al. (2007a); France	Spondee Test	Episodic	20 (*not reported*) 47.2 (5.6)	20 (*not reported*) 48.4 (5.9)	Age and years of schooling	9.9 (2.9) / 11.4 (2.3)	21.8 (8.8); 10-35	9.4 (4.9)	ADP performed significantly worse than CG on spontaneous cued recall, spontaneous recognition and deep free recall.
Loeber et al. (2009); Germany	AVLT BVRT	Verbal Visual	48 (56.3%); 46.5 (8.2)	36 (63.9%); 44.4 (9.9)	Age, gender and pre-morbid IQ	Not reported	12.9 (8.6)	15.6 (6.7)	*Verbal memory:* No significant differences between ADP and CG *Visual memory:* No significant differences were found between ADP and CG
Le Berre et al. (2010); France	Spondee Test FOK	Episodic	28 (75%); 47.9 (5.4); 39-60	28 (50%); 47.8 (5.3); 39-60	Age and education	10.7 (2.3)/ 10.4 (2.6)	11.5 (10.0)	12.8 (7.6)	Conscious recollection in ADP was significantly reduced while familiarity was not.

Daig et al. (2010); Germany	R-OCFT	Visual	25 (100%); 45 (8.41)	15 (100%); 44.2 (11.1); 25-63	Age, sex and education	10 (*not reported*) / 10 (*not reported*)	19.2 (10.2)	7-10	ADP copy accuracy comparable with CG. CG performed better than ADP on immediate and delayed recall
Daig et al. (2012); Germany	VLMT	Verbal	34 (82.4%) 44 (8)	20 (65%) 44.4 (13.1)	Age, sex, schooling and vocational education	10.0 (1.4) / 10.0 (1.4)	18.4 (10.0)	7-10	ADP performed worse in free recall after delay, but not in word recognition
Le Berre et al. (2012); France	Spondee Test FCSRT FOK	Episodic	31 (83.9%); 43.9 (7.0); 31-56	37 (67.6%); 45.5 (6.1); 31-60	Age and education	10.8 (2.1) / 12.1 (3.6)	8.3 (8.3); 0.5-33	12.6 (7.2)	ADP performed more poorly than CG
Wollenweber et al. (2014); Germany	VLMT (German version)	Verbal	22 (72.7%); 46.8 (7.4)	20 (75%); 46.8 (6.5)	Age, gender and education	10.0 (1.9) / 11.0 (1.85)	5 years +	7-21	ADP performed at the same level as CG on learning, direct and delayed memory
Ritz et al. (2014); France	FCSRT (French version)	Episodic	31 (87.1%); 43.8 (6.9); 31-55	31 (64.5%); 45.7 (6.1); 31-60)	Age and education	10.5 (2.3) / 11.6 (3.3)	9.2 (9.3) years	12.6 (7.2)	ADP performed more poorly than CG on learning in the episodic memory task.

ADP – Alcohol Dependent Patients
AVLT – Auditory Verbal Learning Test
BVRT- Benton Visual Retention Test
CG – Control Group
CVLT – California Verbal Learning Test
FCSRT - Free and Cued Selective Reminding Test
FOK – Feeling of Knowing Task
FPT – Figure Position Test
MST – Memory Screening Test
R-OCFT - Rey-Osterrieth Complex Figure Test
VLMT – Verbal Learning and Memory Test
WMS – Wechsler Memory Scale

Matching case and controls

Of the eight studies that found only significant results, seven studies matched for both age and education (Moriyama et al., 2006; Pitel et al., 2007a; Le Berre et al., 2010; Daig et al., 2010; Daig et al., 2012; Le Berre et al., 2012; Ritz et al., 2014); and one matched for age alone (Emmerson et al., 1988). Emmerson et al. (1988) reported that their participants were not matched on either education or verbal intelligence; Le Berre et al. (2010) and Le Berre et al. (2012) reported that ADP had higher depression and anxiety scores than the control group (CG), as well as lower pre-morbid IQ scores. Daig et al. (2010) and Daig et al. (2012) reported that some of their participants had experienced previous alcohol-related seizures, and deliriums on withdrawal from alcohol.

Of the three studies that found only non-significant results, two of the studies matched on age and pre-morbid IQ (this was determined by a verbal intelligence test; Hildebrandt et al., 2004; Loeber et al., 2009), and one matched on age, gender and education (Wollenweber et al., 2014). Loeber et al. (2009) and Wollenweber et al. (2014) also reported on depressive symptoms and found that ADP had more depressive symptoms than CG; Loeber et al. (2009) also reported that ADP smoked significantly more than CG.

Of the three studies that found both significant and non-significant results, all three matched for age and education (Taylor, McGown & Anson, 1997; Mann et al., 1999; Demir et al., 2002), with Mann et al. (1999) also matching on marital status. Taylor, McGown and Anson (1997) included 10 participants in their experimental group who had been diagnosed with ARBD (n=3), traumatic brain injury (n=4) and alcohol-related seizures (n=3). While Mann et al. (1999) matched on education, they reported significant differences between the ADP and CG on measures of verbal intelligence (pre-morbid IQ).

Despite the majority of the studies being matched for age and education, there was a large amount of heterogeneity in the specifics of each group, such as differences in smoking

status, measures of depression and anxiety, and the criteria by which participants were excluded. These variations introduce a certain amount of ambiguity into the results, as there is doubt about comparing 'like for like'. This will be addressed in more detail in the discussion.

Memory

Verbal memory

Of the seven studies that examined verbal memory, five found no differences between the ADP and CG (Taylor, McGown & Anson, 1999; Demir et al. 2002; Hildebrandt et al., 2004; Loeber et al., 2009; Wollenweber et al., 2014). Mann et al. (1999) found no differences in the immediate or delayed recall in the logical memory test, but found that ADP performed significantly worse than CG in immediate recall on the AVLT. Daig et al. (2012) found that ADP performed worse than the CG on delayed recall and learning efficiency. Hildebrandt et al. (2004) found that ADP and CG performed at the same level, however they also included a group of Korsakoff patients and found that these performed significantly worse than both of the other groups on a measure of verbal memory.

Visual memory

Five of the seven studies that examined visual memory reported significant findings when comparing the performance of ADP and CG (Emmerson et al., 1988; Taylor, McGown & Anson, 1997; Demir et al., 2002; Moriyama et al., 2006; Daig et al., 2010). Emmerson et al. (1988) found that ADP performed significantly worse than CG on a test of visual memory. Taylor, McGown & Anson (1997) found that the ADP performed worse than CG on figure recall and also recorded the greater total number of errors. Demir et al. (2002) reported that ADP performed significantly worse than CG on visual reproduction (immediate and recalled)

and visual memory span. Moriyama et al. (2006) found that ADP performed worse than CG on the Figure Position Test. Daig et al. (2010) found significant differences in the immediate and delayed conditions on a visual reproduction test. The remaining two studies reported no significant results.

Episodic memory

All four studies found significant differences between the performance of ADP and CG, with ADP performing more poorly. Pitel et al. (2007a) found that ADP performed significantly worse for episodic memory on spontaneous cued recall, spontaneous recognition and deep free recall than CG. Le Berre et al. (2010) found ADP performed worse than CG in spontaneous cued recall. Le Berre et al. (2012) showed that ADP performed significantly worse than CG on learning, encoding, retrieval and recollection. Finally, Ritz et al. (2014) reported that the ADP performed significantly worse than CG on learning in the episodic memory task. Learning occurred, but they required more trials than CG.

Measures

Mann et al., (1999), Loeber et al. (2009), Daig et al. (2012) and Wollenweber et al. (2014) all essentially used the same test to examine verbal memory, due to the VLMT being based on the AVLT. The results were mixed, with only two studies (Mann et al., 1999 and Daig et al., 2012) finding significant differences between the two groups. However, the differences described were not the same. Mann et al. (1999) found that ADP performed worse than CG on immediate recall, but they performed at the same level on delayed recall. Daig et al. (2012) on the other hand found that ADP performed worse than CG in delayed recall. Hildebrandt et al. (2004) used the CVLT which is similar to the AVLT; there were no significant differences between the groups using this measure.

Three of the studies used the BVRT (Emmerson et al., 1988; Mann et al., 1999; Loeber et al., 2009) to assess visual memory. Only Emmerson et al. (1988) found significant differences between the performance of ADP and CG. Demir et al. (2002) and Daig et al. (2010) both used figure reproduction and recall tests (WMS visual reproduction I and II and R-OCFT respectively). Both found significant differences when comparing the performance of ADP and CG.

Moriyama et al. (2006) used the Figure Position Test, which appears to have been designed by the authors for the study. They found that CG performed better than ADP. Pitel et al. (2007a), Le Berre et al. (2010) and Le Berre et al. (2012) all used the Spondee Test (also developed by the authors) to assess episodic memory. All studies found significant differences between ADP and CG using this test. Ritz et al. (2014) used a French version of the FCSRT. Participants were required to count backwards for 20 seconds between trials. Three free recall trials were administered in order to assess learning abilities. La Berre et al. (2012) used the same method. Both studies found significant differences when comparing ADP to CG on episodic memory.

Overall, a wide range of measures were used to test for a variety of different factors within areas of memory, leading to results that appear inconsistent and somewhat ambiguous. Possible explanations for these inconsistencies are provided in the discussion.

Quality

As mentioned previously, the majority of the studies included in this review had some methodological (or reporting) weaknesses – particularly in the domains relating to assessment of measures and analysis of results. Mann et al. (1999) had the highest quality score with regards assessment of measures. The authors examined both verbal and visual memory, but only found significant results on one of the verbal measures (AVLT). Loeber et al. (2009)

was the highest rated paper overall (69%). They found non-significant results on both verbal and visual memory measures. Wollenweber et al. (2014) was the lowest rated paper overall (31%) and scored only 25% on the assessment of measures. The study reported non-significant results between the groups on verbal memory.

Looking only at studies with an overall score of 50% or higher, three found significant results in visual memory (Taylor, McGown & Anson, 1997; Moriyama et al., 2006; Daig et al., 2010); two found significant results in verbal memory (Mann et al., 1999; Daig et al., 2012); and three found significant results in episodic memory (Le Berre et al., 2010; Le Berre et al., 2012; Ritz et al., 2014). Two studies found non-significant results in verbal memory (Taylor, McGown & Anson, 1997; Loeber et al., 2009).

There does not appear to be a relationship between the quality score and significant or non-significant results within these studies.

Duration of abstinence

While all studies took place within three weeks of abstinence, there was significant variation in the times at which testing took place. The length of abstinence for participants ranged from 2 to 21 days. Visual memory was tested at 11.6, 4.75, 15-21, 13.4, 7-10, 15.6, and 17.8 days. The non-significant results were achieved at 15.6 and 17.8 days. All but one of the significant results (those tested in the 15-21 day range) were tested within 14 days; the non-significant results were achieved after more than 14 days of abstinence. Verbal memory did not show any relationship between length of abstinence and results. Significant results were achieved at 17.8 and 7-10 days; whereas non-significant results ranged from 4.75 – 21 days. Episodic memory tests all achieved significant results which were tested within the first two weeks of abstinence; 9.4 – 12.79 days.

The results indicate that the first two weeks of abstinence may be a period when impairments in both visual and episodic memory can be detected. There does not appear to be a relationship between duration of abstinence and evidence of verbal memory impairment.

Sample size and Power

All of the studies included samples that were of small to modest size, with a range of only 15-49 ADP (and CG ranging from 6 – 49). As mentioned previously, the reports on the analyses were poor with only two studies reporting on effect size (Daig et al., 2010; Daig et al., 2012). They found the effects to be in the moderate to large range. No studies reported on power or confidence intervals and therefore it is difficult to make a judgement on the validity of the results and the associated risk of type I and type II errors.

Discussion

Summary of findings

The aim of this systematic review was to assess the current evidence regarding the impact of chronic alcohol-abuse on memory function in ADP within three weeks of abstinence. The studies reported on verbal, visual, and episodic memory. The results suggest that episodic memory and visual memory are impaired in ADP within three weeks of abstinence, whereas verbal memory is preserved. The heterogeneity of samples and measures used, along with the lack of methodological strength means that clear recommendations cannot be made; however, options for practice are outlined in the section on Implications for Practice.

Context of findings

Lezak et al. (2004) reported on a number of studies that suggested that verbal memory was relatively preserved in ADP (e.g. Bowden, 1988; de Renzi et al., 1984). With only two of the

five studies that examined verbal memory finding significant differences between ADP and CG, this finding is reflected in these results. Visual memory deficits are commonly reported in ADP (e.g. Stavro et al., 2012). The findings of this review agree with previous evidence with five of the seven studies examining visual memory reporting significant results. Similarly, episodic memory deficits are commonly found in alcohol-dependence (e.g. Pitel et al., 2007b; Chanraud et al., 2009). All four studies examining episodic memory found significant differences between the performance of ADP and CG, suggesting agreement with previous research.

Despite this agreement with previous research, it was anticipated that more global deficits would have been seen within the acute three-week period of detoxification after withdrawal (Fein et al., 1990). The neurotoxic effects of alcohol have significant impacts on the physiology of the brain (e.g. Alfonso-Loeches et al., 2013; Sharrett-Field et al., 2013) and it was anticipated that more pervasive memory impairments would have been present during this period.

A wide range of measures and methods was used throughout the studies. Verbal memory was assessed using the MST; WMS; AVLT; CVLT; and VLMT. Studies using the same test achieved different results. For example, both Mann et al. (1999) and Loeber et al. (2009) used the AVLT. Mann et al. (1999) found significant differences in immediate recall (but not delayed), whereas Loeber et al. (2009) found no significant differences in performance. Methodologically speaking, Loeber et al. (2009) had a stronger paper with an overall score of 69% with Mann et al. scoring 54%. Both papers, however, suffered from the same weaknesses, namely in assessment of measures and the analysis and results. Similarly, when examining visual memory, three studies used the BVRT (Emmerson et al., 1988; Mann et al., 1999; Loeber et al., 2009). Emmerson et al. (1988) found significant differences between ADP and CG, while the other two did not.

There were greater levels of agreement in the results from the episodic memory studies, with all four finding deficits using only two tests: the Spondee test and the FCSRT (see Appendix 3). However, it must be pointed out that all four studies were conducted at the same university and by the same research team, which introduces the possibility of bias. It was not possible to clarify whether there was any duplication of participants used within these studies[8]. Therefore, while the evidence within this review seems to indicate that episodic memory difficulties are present within three weeks of abstinence, these results must be interpreted with caution.

Table 5. Summary of dependent variables for neuropsychological measures

Study; year[a]	Neuropsychological assessment measure	Procedure provided	Dependent variables
Emmerson et al (1988)	BVRT	No	BVRT – correct* BVRT – errors*
Taylor, McGown & Anson (1997)	MST	Yes	Word recall Sentence recall Figure recall* Total errors*
Mann et al. (1999)	Logical memory subtest of the WMS	No	Immediate recall Delayed recall
	AVLT	No	Immediate recall*
	BVRT	No	Correct responses
Demir et al. (2002)	WMS	No	Figurative memory Logical memory I Visual paired associates I Verbal paired associates I Visual reproduction I* Digit span Visual memory span* Logical memory II Visual paired associates II Verbal paired associates II Visual reproduction II*
Hildebrandt et al. (2004)	CVLT (German version)	No	Trial 1 Trial 2 Trial 3 Trial 4 Trial 5 Interference Short-term free recall Short-term cued recall

[8] Attempts were made to contact the research team, however to date no response has been received.

			Recognition Recognition errors
Moriyama et al. (2006)	FPT	Yes	Summed time for completion*
Pitel et al. (2007a)	Spondee Test	Yes	Spontaneous % free recall % cued recall* % recognition* Deep % free recall* % cued recall % recognition
Loeber et al. (2009)	AVLT	Yes	Total recall
	BVRT	Yes	Correct responses Errors
Le Berre et al. (2010)	Spondee Test (including Remember/ Know/Guess paradigm)	Yes	Spontaneous % free recall % cued recall* % recognition Deep % free recall % cued recall % recognition Remember answers* Know answers Guess answers
Daig et al. (2010)	R-OCFT	Yes	Copy Immediate* Delayed*
Daig et al. (2012)	VLMT	Yes	First learning cycle Learning efficiency* Total learning efficiency* Reproduction of distraction list Recall after distraction* Delayed recall* Recognition
Le Berre et al. (2012)	Spondee Test	Yes	Encoding – recognition in "spontaneous" condition, Spondee* Retrieval – free recall in "deep" condition, Spondee* Recollection – "R" answers, Spondee*
	FCSRT	Yes	Learning – sum of 3 recall scores FCSRT*
Wollenweber et al. (2014)	VLMT (German version)	No	VLMT 1 VLMT 2 VLMT 3
Ritz et al. (2014)	FCSRT (French version)	Yes	Learning – sum of recall tries FCSRT*

*Significant results

[a] only studies looking at verbal, visual and episodic memory are included in this table

It can be seen from Table 5 that while some studies used the same test, the same dependent variables were not measured. For example, Daig et al. (2012) and Wollenweber et al. (2014) both used the VLMT, however, Daig et al.(2012) reported seven variables, four of which demonstrated significant differences between the groups, while Wollenweber et al.

(2014) only reported on three. In the results, they simply stated that "learning, direct and delayed memory were not impaired in comparison with the control group" (p. 149). Loeber et al. (2009) reported using the AVLT but used an unusual protocol (see Appendix 3) – reading of a 20 word list, immediate recall, followed by a second reading and immediate recall. There were no learning trials, delayed or recognition conditions. These results essentially state that there is no difference between ADP and CG on immediate recall of 20 words. Daig et al. (2012) also found no differences in the first trial of the learning phase on the VLMT, however differences emerged in learning efficiency, recall after distraction and delayed recall.

The results suggest that some tests could be more sensitive to deficits than others within this population. The significant results seen from studies that used a figure reproduction test (e.g. WMS and R-OCFT) suggest the possibility that this type of test may be more sensitive than the BVRT (used by Mann et al., 1999 and Loeber et al., 2009 with non-significant results) to visual memory deficits within this population.

This highlights one of the many difficulties in assessing functioning within this population, as currently there are no validated tests for use in alcohol-dependence (Horton et al., 2014). While none of the tests were validated for this population, some of the studies in this review used well-known, validated and standardised tests (WMS, AVLT, CVLT, R-OFCT) , while others used ones that are less well known (MST), or were created by the authors (FPT, Spondee test). There was no apparent relationship between the significance of the results and whether a well-established test was used; however, using a newly developed neuropsychological measure casts further doubt on the validity of the studies' results.

A number of methodological issues may have affected the results of the studies included in this review. Only two of the included studies (Hildebrandt et al., 2004; Loeber et al., 2009) measured and matched their groups for pre-morbid IQ using a verbal intelligence

test, while the remaining 12 matched on education. The two that matched for pre-morbid IQ found no differences between the groups; however neither study reported on their exclusion criteria for the participants, and while they measured anxiety, depression and smoking status, the groups were mismatched for these factors.

Only five of the studies assessed anxiety or depression (Loeber et al., 2009; Le Berre et al., 2010; Le Berre et al., 2012; Wollenweber et al., 2014; Ritz et al., 2014), despite there being a high prevalence of anxiety and depression in ADP. Conner et al. (2009) reported the lifetime prevalence of major depression amongst alcohol-dependent men and women to be 24.3% and 48.5% respectively. The negative effects of anxiety and depression on cognitive functioning are well documented (e.g. Bierman et al., 2005; Uekermann et al., 2003). In the studies that did measure anxiety and depression, all scores differed significantly between the experimental and control groups. Three of the studies examined episodic memory and found significantly poorer performance in ADP (Le Berre et al., 2010; Le Berre et al., 2012; Ritz et al., 2014); the other two studies found non-significant results in performance on verbal and visual memory (Loeber et al., 2009; Wollenweber et al., 2014). It is surprising that the elevated depression scores in the Loeber et al. (2009) and Wollenweber et al. (2014) studies did not result in poorer performance on memory for ADP (Burt et al., 1995).

Another issue that was not well addressed was the issue of smoking status. There is significant evidence that smoking affects cognitive functioning (Richards et al., 2003; Weuve et al., 2012) and yet apart from one study, smoking was not matched or not reported. The one study that did match for smoking (Demir et al., 2002) found no difference in verbal memory and significant differences in visual memory performance.

The majority of the studies demonstrated weaknesses regarding the exclusion criteria for participants. Of the 14 studies, two studies reported no exclusion criteria for either the experimental or the control group (Hildebrandt et al., 2004; Loeber et al., 2009), however the

majority of the studies excluded on evidence of: neurological problems (including head injury) (n=9); psychiatric disorders (n=10); epilepsy (n=4); serious medical disorders such as diabetes (n=7); and substance abuse other than alcohol (n=9). While excluding these types of difficulties is standard practise in research, the issue when dealing with an alcohol-dependent population is that these exclusions all represent common co-morbidities that are seen in alcohol-dependence (e.g. Morley et al., 2013; Boschloo et al., 2011). Removing participants that experience these difficulties creates the potential for two problems: 1) the patients without co-morbidities are likely to be less complex and to have fewer difficulties (including cognitive impairments) than patients with co-morbidities, and 2) the results are not generalisable to a wider alcohol-dependent population.

There is a large body of evidence that reports on the variability of difficulties within an alcohol-dependent population. Fein et al. (1990) reported that 50-67% of abstinent alcoholics exhibit cognitive impairments during the first months of detoxification, and Bates et al. (2002) similarly found that 50-80% of alcoholics experience neuropsychological deficits. While these figures relate to cognitive impairments generally, rather than memory specifically, both Fein et al. (1990) and Bates et al. (2002) specifically refer to memory as one of the commonly impaired areas.

This broad range of possible deficits introduces a potential risk when looking at small sample sizes of ADP due to the individual variability. The sample sizes of the included studies ranged from 15 – 49 ADP. These are relatively small samples, and, as a result, the studies run the risk of being underpowered, however power was not reported in any of the studies. Small samples could result in a failure to identify differences which exist between the sample groups, leading to non-significant results. Likewise, the wide variability in reports of neuropsychological deficits in ADP, coupled with the small sample size, makes it possible that the results are not generalisable to the wider alcohol-dependent population.

Strengths of review

The potential for subjective bias was reduced in this review by the use of independent raters both for full-text screening and quality assessment. The high degree of inter-rater reliability strengthens the validity of selection and scoring. Potential for bias was also limited by corresponding with authors where appropriate to gain additional information about papers. For example, two papers were excluded from the review as they utilised the same participant sample as two that were already included.

Limitations of review

There are a number of limitations within this review. Only articles available in English and that had been published were reviewed. Also, a limited number of appropriate electronic databases for the subject matter were searched, leaving the possibility that relevant papers may have existed within unsearched databases. Only two journals were hand-searched over a period of five years; searching more may have yielded more papers. Similarly, only the studies included in this review were reference-searched.

In addition, this review included studies where assessment of memory was carried out, but was not the primary focus of the study. Four studies looked exclusively at an area of memory (Taylor, McGown & Anson , 1997; Le Berre et al., 2010; Daig et al., 2010; Daig et al., 2012) whereas the remaining 10 studies included a measure of memory as part of a wider neuropsychological battery.

A number of further limitations within this review were the result of pragmatic decisions made due to constraints associated with the development of this doctoral thesis. This review would have been a more robust, and potentially more clinically useful study, had it reviewed the full neuropsychological profile for alcohol-dependent patients within three

weeks of abstinence. This would have provided an overall picture of the functioning of patients as they emerged from detoxification/withdrawal, and would have provided clinicians with evidence on which to base treatment decisions. However, it would not have been possible to complete this piece of work within the time-frames and other constraints available, and therefore a decision was made to examine one of the main areas (memory) which is frequently highlighted as being particularly problematic within alcohol dependence (e.g. Lezak et al., 2004). While this current review does not provide the 'complete picture', it does provide clinicians with information regarding areas to consider when planning their treatment protocols and future research.

Another decision that was made was that of excluding working memory. Working memory is often considered to be part of executive functioning, and in order to make the results as clear as possible, the decision was made to exclude it. On reflection, including working memory may have clarified the profile of this population regarding functional memory. Its function in 'real life' is to hold information in mind for short periods – such as when being introduced to people and following spoken instructions. As such, there is potential for this to impact on a patient's ability to take part in treatment, and therefore should have been included within this review.

It was not possible within this review to have the abstracts reviewed by another clinician due to the lack of availability of colleagues to carry out this work, and it was felt that second ratings were more valuable at the full-text level and for the quality criteria. A second reviewer at the abstract level would have reduced the potential for bias (and error) in which papers were rejected, and which were progressed to the full-text review.

The decision was made to exclude dissertations from this review due to them having not been through a peer review process for publication. However, on reflection, the fact that a dissertation will have gone through a rigorous examination process within the associated

university makes it likely to be of a similar calibre to published papers. The implication of excluding them is that they may have provided data which could have further clarified the results of this review.

Studies were included if participants had been abstinent for less than three weeks, however, no exclusion criteria were developed to exclude participants who were still undergoing the acute physical effects of withdrawal. Many of the studies did not test participants until after these effects had dissipated, however, specifying this as an exclusion criterion would have strengthened the quality of the review.

The inclusion criteria for the studies in this review included a healthy control group. It was felt that it would offer a clearer view of functioning to compare the participant group under review (ADP) with a normal sample. In retrospect, as this review was looking for impaired functioning at a particular time point, it would have been possible to compare results to normative values. This could have allowed access to more papers, thereby making this review more robust. It also would have enforced the need to only select papers which used validated tests which had normative data available, thereby increasing the quality.

Leading on from this, the quality criteria within this review were also perhaps not as robust as they could have been. One of the issues that came out in the review was the fact that studies did not use the accepted procedure for the neuropsychological measure of memory. It would have been helpful to include this as a quality criterion in the early stages as it would have highlighted the studies which used unusual procedures. Similarly, aspects of the study that were not considered include sample size and study design. More focus on these aspects, may have produced a clearer picture of the studies that presented the most robust and valid results.

Implications for practice

Governmental guidelines prescribe the need for a comprehensive assessment covering a number of different areas to establish a full picture of patient needs in order that the most appropriate and effective treatment/service is provided (Scottish Government, 2008). The Healthcare Quality Strategy (Scottish Government, 2010) actively promotes this type of person-centred approach and states that each path to recovery should be unique and individual. While the ambiguity of the results reported here may partly be as a result of weaknesses in methodology, it is likely that multiple factors 'muddy' the picture with regards the impact of alcohol-dependence on memory functioning (i.e. education and IQ; Bates et al., 2002). This review emphasises the necessity to assess patients on an individual basis and prepare treatment programmes that are tailored to their particular needs. As such, cognitive screening for patients with alcohol-dependence entering a treatment programme is vital in order to determine any areas of weakness that might need additional support through the treatment process. The need for this individually tailored approach to treatment is emphasised by the variability of the results that are seen within this review.

The results suggest that the areas that are likely to be impaired are episodic and visual memory. As already mentioned, patients should be individually assessed for impairment in these areas in order to support them through treatment. With episodic and visual memory deficits patients are likely to find that they have difficulties such as remembering people's names and faces, recalling the current date, or remembering to attend appointments in the future. They may also have difficulty with spatial navigation and way-finding.

For patients experiencing these difficulties, there are clear implications regarding being able to attend and respond to treatment and as such, clinicians need to be prepared to support these deficits. There are two main approaches that can be taken to memory impairments, restoration or rehabiliation of the function and compensation. There is a wide

range of evidence on the rehabilitation of memory functions, including a recent systematic review on the difficulties seen in alcohol-related brain damage (Svanberg & Evans, 2013). Within clinical practice, while rehabilitation may not be possible in the early stages, compensation provides simple solutions to support deficits – these include the use of external aids such as notebooks, planners and smart phones (Sohlberg et al., 2007).

Implications for research

While all studies examined aspects of memory using neuropsychological measures, the disparities in participant selection, measure selection, quality and design mean that it is difficult to compare the results 'like for like'. As far as possible, patients and controls need to be matched for known confounders (which would require the inclusion of patients with known co-morbidities) in order to get a clearer picture of memory function in this population. The reporting of participant selection and exclusion needs to be more explicit, not least to allow for replication of results. Finally, analyses need to be more transparent and informative: reporting power, effect size and confidence intervals in order to give more meaning to the results that are presented.

Research needs to be focused on the validation of tests for use within this population – for both research and clinical purposes. Standardised screening would also allow more accurate profiles to be generated about the types of difficulties experienced at different time points of treatment – and much larger samples which would help eliminate the 'noise' generated by the variability amongst patients.

Finally, it would be enlightening to see more specific research carried out within this time-frame, using validated tests, and in studies that are designed to test specifically for memory impairments. While it seems likely from the evidence base that verbal memory is relatively preserved, while visual and episodic memory are not (which is somewhat supported

by the results of this review), it would be useful to have more concrete evidence so that more specific treatment guidelines can be developed.

Research Agenda

The following are specific areas which need to be addressed in order to further the knowledge-base regarding this population:

- Validation of neuropsychological assessments for this client group is vital. Both to improve the assessment process in clinical practice and to improve the quality of research and the resulting knowledge base.
- A review of the full neuropsychological profile at different time-points throughout the alcohol-recovery journey in order to better understand the difficulties experienced by this population, as well as the trajectory of recovery. Ideally, this would be using specific, validated assessments, using specific protocols.
- In order to research this population, it is necessary to include those with conditions that are more usually excluded from research. This would include factors such as head injuries; psychiatric and mental health difficulties; physical health difficulties; as well as other substance misuse. Difficulty arises in managing the 'noise' that is generated by all of these potentially confounding factors. Careful and well reported methodological design will be required, together with appropriate statistical applications such as using a general linear model in order to co-vary these confounding factors.
- It will likely remain difficult to fully understand and research the functioning of this very complex population. However, good quality, well-reported studies, and large volumes of this type of research will help to manage the difficulties in studying this

population, and will result in a clinically relevant emergent profile of this client-group.

Conclusions

Fourteen studies were reviewed to determine the impact of chronic alcohol-abuse on memory within three weeks of abstinence. The results of this review indicate that memory difficulties are present within the first three weeks of abstinence, particularly in episodic memory and verbal memory. However, due to the heterogeneity of the studies, coupled with the methodological variability, all conclusions must be considered to be tentative, and be interpreted with caution. The main difficulties with interpretation are to do with the confounding factors often found within this client group. The results reinforce the concept of tailored treatment programmes for individuals due to the large variability of the effect of alcohol (and other factors). Finally, methodological rigour and transparency should be paramount when reporting on such a complex and variable population.

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Research Article

Transformation through adaptation: A grounded theory of the patient experience of Alcohol-Related Brain Damage[9]

Heather Jayne Simpson*, University of Edinburgh, NHS Lothian, Edinburgh, UK

Jenny Svanberg, NHS Forth Valley, Stirling, UK

Ethel Quayle, University of Edinburgh, Edinburgh, UK

Suzanne O'Rourke, University of Edinburgh, Edinburgh, UK

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(excluding abstract and references)

**University of Edinburgh, School of Health in Social Science, Medical School, Teviot Place, Edinburgh, EH8 9AG*
Tel: (+44) 131 651 3972
Email: heather.simpson@nhslothian.scot.nhs.uk

[9] Written in the style of the journal Neuropsychological Rehabilitation – see Appendix 6 for author guidelines

Transformation through adaptation: A grounded theory of the patient experience of Alcohol Related Brain Damage

Aims: This study aimed to develop a grounded theory regarding the patient experience of alcohol-related brain damage (ARBD), identifying and highlighting themes and concepts that are central to the experience.

Methods: Grounded Theory was used to analyse interviews with 10 adult participants who had ARBD. Data was analysed using line-by-line, focused and theoretical coding, leading to the creation of theoretical categories.

Results: This model hypothesises that successful negotiation of the journey through ARBD hinges on the adaptations that need to be made in order to progress towards transformation. The model is understood in the framework of a number of phases, "*Being diagnosed with ARBD*, "*Focusing on abstinence*", "*Taking ownership of life with ARBD*" and "*Creating a valuable life*", all of which exist within a framework of support by specialist services.

Discussion: Adaptation appears to play a key role in the successful negotiation of a diagnosis of ARBD, and this study proposes a series of categories that can be used as a framework to identify and support the changes that are necessary for recovery and reintegration. The value in this study is that the results are directly attributable to individuals who have been diagnosed, and are now successfully living, with ARBD.

Word count: 200 words

KEYWORDS: ***alcohol-related brain damage; ARBD; recovery; rehabilitation; grounded theory***

Introduction

Alcohol-related brain damage (ARBD) has emerged as a term to explain the range of effects that long-term consumption of alcohol can have on the structure and function of the brain. ARBD was initially understood as a condition related to a number of causes, including: the toxic effect of alcohol on the physiology of the brain; vitamin and nutritional deficiencies; head injuries; and interruptions of the blood supply to the brain (Cox, Anderson & McCabe, 2004). It is now thought, however, that the specific range of difficulties seen in ARBD are due to the impact of thiamine and other nutritional deficiencies on the brain (e.g. Zahr, Kaufman & Harper, 2011; Martin, Singleton & Hiller-Sturmhöfel, 2004). While alcohol use increases the risk of both injuries and vascular disorders, these would not normally be classified as ARBD.

ARBD tends to be diagnosed in patients in their forties and fifties, with females experiencing symptoms a decade earlier than males (Royal College of Psychiatrists, 2014). Symptoms range from the classical presentation of Wernicke-Korsakoff's syndrome to 'milder' but more frequent deficits seen in frontal lobe functions (Royal College of Psychiatrists, 2014). Wernicke's Encephalopathy (WE) is an acute neuropsychiatric disorder caused by thiamine deficiency: it has historically been diagnosed via a triad of mental status changes, ophthalmoplegia and ataxia (Isenberg-Grzeda, Kutner & Nicolson, 2012) although research has suggested that it can present with only one or two of these changes (Pitel et al., 2011). WE can progress to Korsakoff Syndrome which presents with impaired memory formation while other cognitive functions are preserved, and in the presence of confabulation (Isenberg-Grzeda et al., 2012).

ARBD is the result of a range of neuropathalogical changes, cerebella-cortical damage and changes in the cerebral hemisphere, in particular the dorso-lateral frontal cortex (Matsumoto, 2009). These changes often result in cognitive impairments, which can interfere

with an individual's ability to function independently, specifically in areas such as memory, attention, planning, judgement and processing of new information. These difficulties are often accompanied by personality and behavioural changes (Cox et al., 2004), which can result in increased risk behaviour (Bjork, Momenan, Smith & Hommer, 2008). Importantly, ARBD has the potential for recovery (Kopelman, Thomson, Guerrini & Marshall, 2009). Research by Victor, Adams & Collins (1971) suggested that 25% of people make a full recovery, 25% make a partial recovery, 25% make minor recovery and 25% make no recovery, meaning that 75% of patients diagnosed with ARBD have scope for some level of recovery with the right treatment and rehabilitation (Cox et al., 2004).

The impact of ARBD is not limited to cognitive functioning, but can also lead to reduced quality of life, mood disorders, mobility and physical health problems (MacRae & Cox, 2003; Zahr et al., 2011; Aziz, 2014). Significantly, it can also jeopardise an individual's ability to live an independent life (Ganguli, Vander Bilt, Saxton, Shen & Dodge, 2005). The complexity of the difficulties that this patient group experiences often results in them falling between services. General adult and alcohol treatment services may have difficulty in providing for patients with significant cognitive deficits, due to a lack of facilities, resources or experience in being able to manage and rehabilitate these types of difficulties. Similarly, dementia services may not possess the appropriate knowledge regarding alcohol-abuse to properly cater for people with ARBD (Wilson, 2011). The treatment and support required for a progressive condition such as dementia is quantifiably different than that required for ARBD which has the potential for significant improvement. Those patients that do not fit well within existing services are prone to readmission, and without access to appropriate and needs-led services, have higher morbidity and increased mortality (Price, Mitchell, Wiltshire, Graham & Williams, 1988).

A further discrepancy between dementia services and ARBD services is that there has been a great deal of research to date into the lived experience of dementia (e.g. Harman & Clare, 2006; Harris & Keady, 2004) which has been used to inform both service development and care planning. While ARBD research is beginning to gather momentum, there are currently very few examples of research which give voice to the lived experience of ARBD. Research is progressing, however, and one important piece of research outlines a formalised approach to rehabilitation in ARBD. This model, described by Wilson et al. (2012), is made up of five overlapping therapeutic phases: physical stabilisation; psycho-social assessment; therapeutic rehabilitation; rehabilitation; and social integration and relapse prevention. This is the first published attempt to create a treatment pathway for patients diagnosed with ARBD. Svanberg and Evans (2013) have further advanced this area of research by producing a systematic review of neuropsychological rehabilitation approaches for ARBD. This review provides a useful overview of the current research regarding cognitive rehabilitation strategies and makes suggestions for clinical practice, such as allowing patients extra processing and retrieval time when providing information; the use of repetition and/or memory aids; and providing clear rules for action. This review also further highlights the gaps in the current evidence base and the need for further research.

There have been a number of recommendations over the last decade calling for greater education and awareness regarding patients with ARBD (e.g. Cox et al., 2004, Scottish Executive, 2006), as well as the need to better understand the issues and difficulties experienced by people with ARBD and to incorporate their views into planning and developing services (Cox et al., 2004). Despite this, there remains an absence of national guidance on service provision and care pathways. An accurate estimation of the size of the problem is difficult to define, as many patients remain un-diagnosed (Royal College of Psychiatrists, 2014), and there is a lack of standardised diagnostic and assessment tools

(MacAskill, Cooke, Eadie & Hastings, 2001; Horton, Duffy, Hollins Martin & Martin, 2014). Specialist services do exist, although they are few and far between with only four such services currently available in the UK (3 in Scotland and 1 in England).

While the research field within ARBD is expanding (see Royal College of Psychiatrists, 2014), a significant gap that exists in the current literature is that of the account of the lived experience of people with ARBD. Keady et al. (2009) carried out a qualitative study of six patients with ARBD, the results of which further emphasised the need for specific, tailored services for these patients, focusing on rehabilitation and quality of life. In order to fully meet the needs of patients with ARBD, it is essential to first gather information about their needs and experiences of living with the condition. The only way to achieve this is by asking them.

Aims

This study aimed to develop a grounded theory regarding the patient experience of ARBD, identifying and highlighting themes and concepts that are central to the experience. It is hoped that this information will lead to the development of shared understandings and meanings which can be used to enhance service provision.

Methods

As there is very little current research into the patient experience of ARBD, grounded theory (a qualitative approach) was chosen to explore the experiences of those with ARBD and to develop a theoretical position that might help inform future research and practice. Glaser (1978) stated that this approach could be used to go beyond preconceptions in order to identify the processes underlying patient experiences, so that professionals could use this information to help with the patient's primary concerns.

Design

This research adopts a constructivist view of grounded theory, which does not disregard the researcher's perspective, but rather includes it as a necessary and integrative part of the theory (Charmaz, 2014). Factors that are likely to have influenced the interviewer's (HJS) interpretation of the data include her training in clinical psychology, previous experience of working with a substance misuse population, as well as her personal experiences. The quality of the research was evaluated using criteria suggested by Charmaz (2014) which include credibility, originality, resonance and usefulness.

Credibility

Credibility considers the links between theory and data and how well these are represented and supported. For this study, empirical data was collected via interviews, a focus group and field notes in order to develop the theory. The analysis consisted of line-by-line coding, focused coding and theoretical coding, which was enabled by memoing, constant comparison and reflective processing. Two psychology colleagues also carried out line-by-line coding on two transcripts in order to verify and validate the emerging themes. Credibility has been further demonstrated through the use of quotations to highlight the links between the data and the argument, and exhibit the depth of data which support the theoretical claims.

Originality

Originality is used to evaluate whether the study posits an original theory which offers new insights into the area of research. This study claims theoretical significance as the lived experience of ARBD has rarely been researched. The finding that the successful negotiation of the diagnosis of ARBD is achieved through a process of adaptations provides new

information for potential service and treatment planning, as well as avenues for future research.

Resonance

Resonance is intended to evaluate whether the grounded theory categories relate to the experience of ARBD and whether the categories make sense to participants diagnosed with ARBD. For this study, resonance was evaluated through the use of a focus group. The participants within the group felt that the emergent theory made sense and that is was a valid representation of their experiences.

Usefulness

Usefulness is concerned with the practicality of the research, of whether it can be used as a springboard for further research and whether it contributes to knowledge. The grounded theory presented in this study offers interpretations of the experience of ARBD which can be used by support services to help develop treatments and programmes, as well as highlighting a number of interesting areas which can be researched further (see Discussion).

Ethical approval

Prior to commencing the study, ethical approval was granted by the Integrated Research Application System (IRAS; see Appendix 4 for relevant paperwork). Fully informed and written consent was obtained from all participants prior to participation and consideration was given to the interview format to ensure minimal risk of discomfort or distress. Confidentially and anonymity were discussed prior to each interview, and participants were reminded that participation was voluntary and that they were able to opt out of the research at any point without penalty.

Participants

In order to participate in this research, participants were required to be over 18 years of age, to have a diagnosis of ARBD, to be able to communicate verbally, and to have the ability to consent to taking part in the study. The only specific exclusion criterion was if the participants were known to be currently misusing alcohol. Participants were recruited from, and with the assistance of, the ARBD team, an integrated serviced managed by both the NHS and Council of a large urban settlement in the west of Scotland. Patient referrals into the ARBD service were taken by letter or phone, and came from a variety of referrers from health, social care and the voluntary sector.

Participants were all patients within the ARBD team, which provided them with practical, psychological and medical support with regards their condition. Other third sector organisations were also involved and worked alongside the ARBD service to provide support with accommodation and other welfare needs.

Participants were invited to take part in the study by a member of the ARBD team. They were provided with the participant information sheet and participant consent forms (see Appendix 5) once the study had been explained to them and they had indicated an interest in taking part. Participants were given a minimum of 24 hours to consider the information and whether they wished to proceed before the interview appointment was arranged. The ARBD team arranged all appointments. Ten people were interviewed, all in their own accommodation. Following the individual interviews, a focus group of service users was conducted, in order to validate the emergent theory. This was carried out at the ARBD team offices.

Eleven participants were invited to take part in individual interviews. Ten participated; one participant was unable to take part due to ill health. A further four participants took part in a focus group at the end of the study.

The participants lived in a variety of accommodation including residential care, supported accommodation and their own homes. The duration of alcohol problems ranged from less than 10 years to over 30 years. Participants came from a range of educational and occupational backgrounds; some leaving school without sitting any examinations while others went on to gain professional qualifications. None of the participants were in employment at the time of the interviews. Table 6 summarises the demographics of the participants.

Table 6. Participant demographics

Participant	Age range (years)	Sex	Time involved with ARBD service (years)
Participant 1	55-60	M	0.8
Participant 2	55-60	M	4.6
Participant 3	50-55	M	0.3
Participant 4	40-45	M	1.2
Participant 5	55-60	F	0.6
Participant 6	55-60	F	5.8
Participant 7	50-55	M	1.9
Participant 8	65-70	F	3.9
Participant 9	50-55	M	1.1
Participant 10	40-45	M	1.2
Range	*40-67*	*7 M, 3 F*	*0.3-5.8*
Mean (SD)	*53.8 (7.9)*		*2.1 (1.9)*
Focus 1	55-60	F	2.1
Focus 2	45-50	F	0.8
Focus 3	50-55	M	0.7
Focus 4	60-65	M	4.7
Range	*46-62*	*2 M, 2 F*	*0.8-4.7*
Mean (SD)	*55.8 (6.9)*		*2.1 (1.9)*

Theoretical sampling

Patients with ARBD are a challenging population to research as there are a myriad of difficulties in accessing this population. These difficulties can include cognitive impairment and intoxication, both of which can affect capacity to consent; which can severely restrict appropriate potential participants. There is also no clear way of identifying patients with ARBD, unless they are connected in to services. At the time of data collection, there were few ARBD services within Scotland which meant that convenience sampling, rather than theoretical sampling, had to be used in order to study this population.

Data collection

Semi-structured interviews were recorded on an Olympus DS-3400 digital voice recorder,, transcribed verbatim (including pauses, hesitations, and retaining dialect), omitting or changing any information that could potentially identify the participant. The recordings were transcribed after each interview and, in accordance with grounded theory methods, initial coding was carried out alongside further data collection. These were then used to inform and direct subsequent interviews.

Memo-writing is considered to be a crucial method within grounded theory (Charmaz, 2014), and is a way of recording thoughts, insights, feelings and ideas as they occur through the data collection and analysis phases (Birks & Mills, 2011). Memoing was used throughout this study enabling the capture of early theoretical insights, and assisting with raising focused codes to theoretical categories.

Analysis

Data analysis involved a process of initial line-by-line coding, focused coding which was then followed by theoretical coding (Charmaz, 2014). For validation purposes, two transcripts were also given to colleagues to code, to act as a comparison and to reduce researcher bias through critical discussion.

Results

This study proposes a theoretical model of the pathway that participants have used/developed in order to navigate through the diagnosis of ARBD and ultimately transform their lives to successfully live a valued life with ARBD. A brief description of the full model will be followed by an in-depth explanation of the conceptual categories contained within.

The model describes a journey towards transformation that is achieved through personal and environmental adaptations. The process begins with a diagnosis of ARBD and progresses towards participants being able to create a valuable life. Between these two categories there is a focus on abstinence, which differs in quality depending on the time-point within the journey. Transformation hinges, in part, on the process of starting to take ownership for managing life with ARBD. For these participants, this whole process exists within a framework of being supported by specialist services, which enables participants to activate their skills, abilities and determination to move towards a positive position whereby they are able to successfully manage their condition.

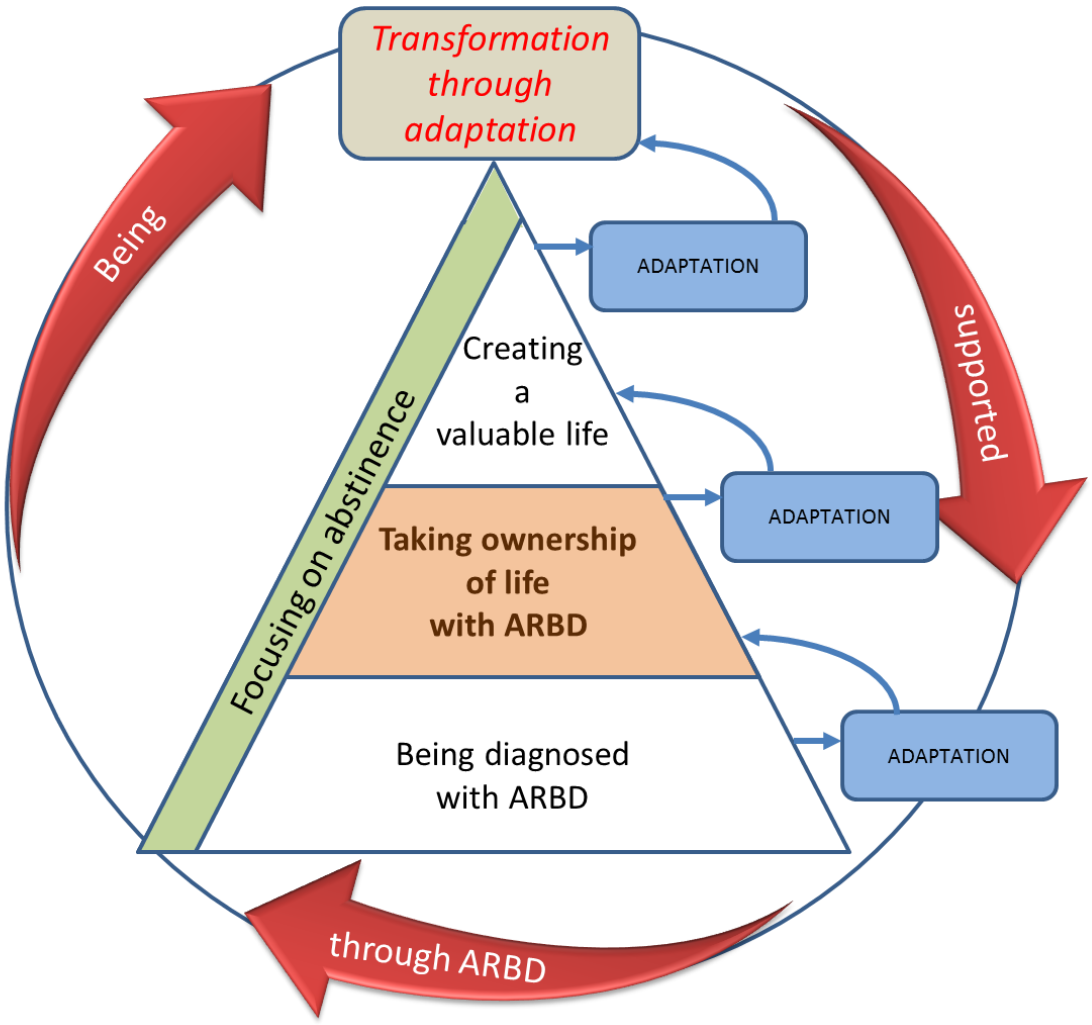

Figure 1. The process of transformation through adaptation following an ARBD diagnosis.

Transformation through adaptation

The overall core theoretical category was identified as "Transformation through adaptation". The process of transformation appeared to be connected to a wide range of adaptations that allowed the participants to progress from a very difficult position post-diagnosis, to a point where they could begin to rebuild their lives and start creating one that had value for them. The adaptations that were required were many and varied, and can be understood within the framework of a number of stages. The model of "Transformation through adaptation" describes the adaptations made by participants at each of the stages, or subcategories,

identified as : “Being diagnosed with ARBD”; “Focusing on abstinence”; “Taking ownership of life with ARBD”; “Being supported through ARBD”; and “Creating a valuable life”.

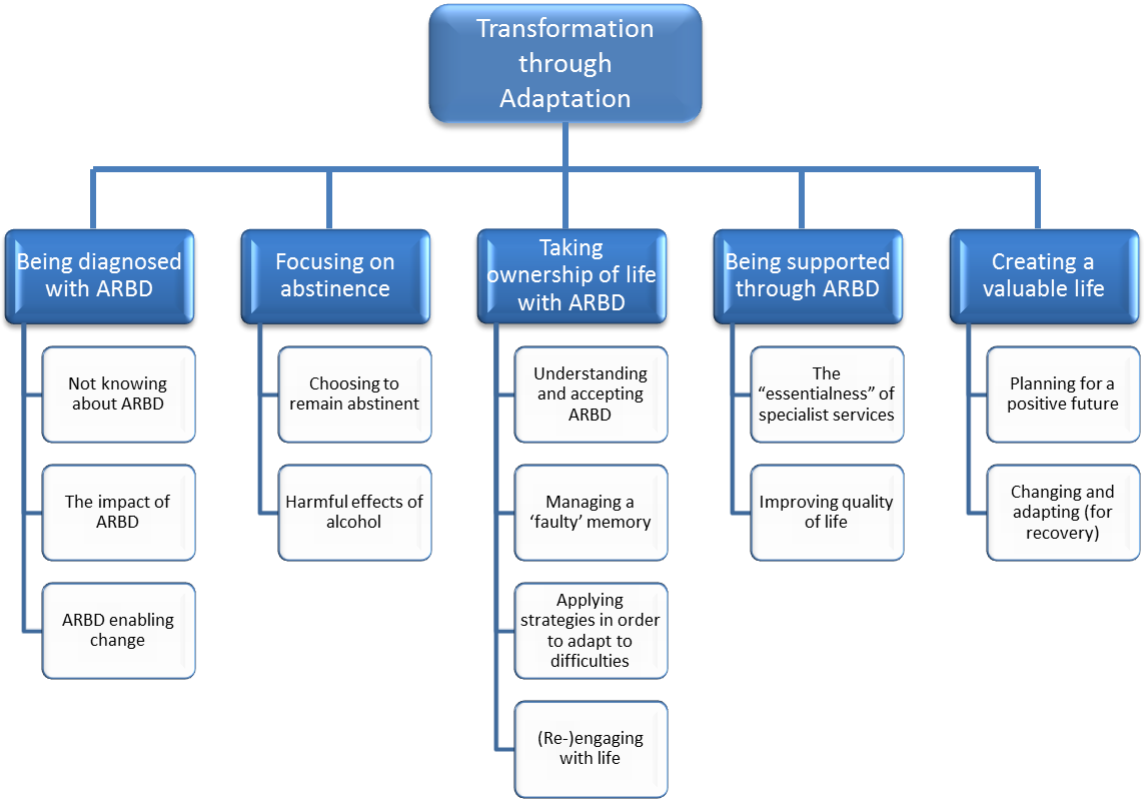

Figure 2: Overview of conceptual categories

The subcategories and associated themes are reported in this section. Extracts from interviews are included throughout in order to enhance understanding and increase transparency regarding how the themes were developed.

Being diagnosed with ARBD

The process of being diagnosed with ARBD was described as a difficult and confusing time. The diagnoses were often made at times when participants were physically unwell, cognitively impaired and often socially and physically neglected. There was a distinct lack of understanding about ARBD generally and this led to confusion and uncertainty for the

participants. The description of their experiences led to the development of three main themes within this category: 1) "*Not knowing about ARBD*"; 2) "*The impact of ARBD*"; and 3) "*ARBD enabling change*".

Not knowing about ARBD

A significant issue for the majority of participants was the lack of knowledge regarding ARBD. It was likely that participants were very unwell in hospital when being diagnosed, so were often not in a position to fully understand what was going on, or to retain clear memories about their admission:

> *P1:* I can't really remember very much about the hospital.....
>
> *F1:* I thought I was in [hospital] for an operation

It was very apparent that participants had no previous knowledge of ARBD, which was on occasion compounded by a similar professional lack of understanding:

> *P3:* I've been to the doctor's once before as well and I did say to the doctor that I'd been diagnosed with ARBD, and he asked what that was……. He didn't have a clue. There are folk walking about just now, not even realising that they've got ARBD….you know

There was also a general misunderstanding regarding the aetiology and pathology of ARBD, leading to some confusion as to how they could be experiencing the symptoms and difficulties that they were presenting with. And of course, this misunderstanding was occurring (mostly) at a time of acute alcohol toxicity coupled with cognitive impairments:

P6: Oh, what's that, you know what I mean and then they telt me Korsakoff, I went what's that.....I thought it was a disease. I thought it was something that was.....

R: Right, like you could catch or something, uhuh?

P6: Uhuh, aye, uhuh. I'm saying what is that? I thought it was something like that .....know what I mean

The impact of ARBD

As patients began to understand the implications of being diagnosed with ARBD, many described receiving the news as catastrophic:

P7: Know it did hit me for six know so it did when eh obviously well I've got it but I was know I ju, I just kept refusing. I said tae the person no, no you're wrong so it was, no

P8: ..because when you're diagnosed wi' ARBD [clap] you think the whole world's fell apart

It was apparent from their descriptions that the diagnosis was received by participants as serious, significant and life-changing.

ARBD enabling change

Many of the individuals interviewed described the diagnosis as a turning point:

P4: It's turned ma whole life right around now

P8: I think when I was diagnosed wi' ARBD that was a turning point in ma life

The changes that occurred within participants from the point at which they received their diagnosis, to the point at which they were able to start making changes was achieved through a process of adaptation. This process allowed them to move from a difficult, hard to understand and often distressing diagnosis, towards a change in behaviour which would start to improve their lives:

> *P8:* But I think being diagnosed wi' the illness made you realise alcohol's not for you.

Taking ownership of life with ARBD

The participants in this study described a series of processes, which allowed them to take ownership of their condition and make significant improvements. The themes identified within this category were 1) "*Understanding and accepting ARBD*", 2) "*Managing a "faulty" memory*", 3) "*Applying strategies in order to adapt to difficulties*" and 4) *"(Re-)engaging with life*".

Understanding and accepting ARBD

Participants described a number of features related to understanding and accepting their condition. They discussed how living with ARBD involved living with uncertainty, which was related to the 'unreliability' of their memory:

> *P1:* I don't know if I would remember.

> *P5:* and if I hudnae a done [marked mother's death on the calendar] that I would still've been thinking she was still living.

They described the process of accepting changes (physical and social) and the difficulties associated with this:

> *P6:* You get used tae it efter a while.

> *P7:* So I just like need tae accept it and just get on with life.

They also described how they benefitted from the knowledge of specialist services which led to better understanding of their condition. This enabled them to adjust their expectations and begin to take responsibility for their condition and the adaptations that would be necessary to progress:

> *P9:* Definitely making a difference in ma life because fae I've started working wi' the ARDB [team], it lets me know what's wrong wi' me

Managing a "faulty" memory

A key feature of managing life with ARBD appeared to be the ability to manage the associated memory difficulties. Managing a 'faulty' memory was primarily described as an effortful process ("trying to remember"), which is at odds with what they considered to be 'normal':

> *P1:* Well, the thing that stands out most is forgetting things that mmmm, trying to remember just a couple of days ago what I done

> *P6:* I'd need tae sit and think ah what did I dae, do you know whit I mean?

There was an acceptance of the unreliability of memory and the fact that participants had to relearn ways of doing things:

P9: like if I've, up to and try tae jog the memory and keep ma memory going so it is and try ma best know tae think ae things

P6: I mind one day and like next day I might no mind anything.

There was a significant element within this category where the majority of participants described "remembering the past, but not the present":

P6: I can mind ae the past, but see likes ae yesterday, I've got tae try and think what I had done yesterday.

P8: Don't know. But that could've happened 30 year ago and I could tell you word for word.

Applying strategies in order to adapt to difficulties

Participants described the necessity of the use of strategies to manage memory difficulties, such as whiteboards, diaries, and calendars to 'store' memories. Multiple strategies were employed, and participants displayed flexibility and adaptability in managing their needs:

P8: But now whit ah do is I've got a pad and a pen beside me bed beside ma telephone.

Routine was also shown to be of significant importance to the participants. It added structure and predictability into their days and supported their improvements. Routine events were described as being significantly easier to manage than unexpected or adhoc events:

P1: then it's okay because it's every day. A routine like that, yeah, but if, something you only do once a week, or once a fortnight....

P8: Well what I do, I've got a structure. I've got tae build a structure in tae ma life with havin' ARBD

(Re-)engaging with life

Once participants had begun to manage the practical difficulties associated with ARBD, it became apparent that they were entering a process whereby they were beginning to 're-engage with life'. They demonstrated this through the reclaiming of their independence (going out on their own, moving into their own accommodation, adapting, or learning new skills and finding pleasurable activities):

P1: Uh, I go myself. [My brother] took me the first couple of times you see showed me how to get there and now I'm gonna go on the bus myself and come back

P9: Eh I had tae re, relearn sort of ma, how basically tae run ma house and things like that.

P8: Likes of when I get up in the morning, you have your breakfast and then di, you do different things. One o'clock ye know your gonny have your lunch but when I was diagnosed at the beginning I never had a structure in place. I was all over the place. It takes ye a wee while tae build in to yourself your own confidence

P5: In fact I won the quiz. Well there was 4 ae us sitting at the table last night and we won the quiz last night.

It is clear from the participant accounts that while there was a significant amount of work and effort devoted to their recoveries by themselves, there was also a crucial role played by specialist services in supporting these changes and development.

The process that was key within this category was one of adaptation. Without developing the necessary knowledge, acceptance and adaptations, patients would not be equipped to move forwards towards a transformed life.

Focusing on abstinence

Participants gave a significant number of examples of how they were managing their abstinence, with the help of specialist services. They demonstrated positive and helpful strategies (such as the use of mood diaries to highlight the association between reduced mood and increased cravings; keeping busy; distraction). There was considerable pride evident in declaring their abstinence. However, the focus on abstinence changed over time.

Early in recovery, thoughts were related predominantly to cravings and relapse management, but as participants remained in recovery, the focus shifted to maintaining their abstinence. The main themes developed within this category were: 1) "*Choosing to remain abstinent*" and 2) "*The harmful effects of alcohol*".

Choosing to remain abstinent

It was clear from the frequency with which participants discussed alcohol that it was still a prominent feature in their lives, no matter where they were in their recovery journey. However, what became clear during analysis was that the focus was actually on remaining abstinent as opposed to drinking per se.

While participants described their diagnoses as a pivot point for the commencement of change, it is likely that abstinence is imperative in maintaining this change and allowing

individuals to continue moving forward. Participants emphasised on multiple occasions that they would not go back to alcohol, and that they were choosing to remain abstinent:

> *P1:* Nah, no, gonna go back on the drink at all, you know

> *P8:* I can live a normal life at the moment.....As long as I don't touch alcohol

> *P2:* ..and it induces problems. It exacerbates your problem and the only thing is you can do is it might be hard, you might be get a bit uptight wi no drinking but ye start tae see it's the sensible way to be...

There was a significant sense of pride which echoed the difficulty which is associated with maintaining abstinence:

> *P4:* ...in there, but this is the longest I've stayed aff it so far since I've been oot [facility name].....But I'm just thinking I'm gonny beat ma record, ma longest was 8 weeks

Participants who were more recently abstinent were more likely to discuss the issues relating to cravings and relapse. It is unlikely that these had ceased to be issues for participants further on in recovery, but they had become less 'urgent':

> *P7:* [The cravings are] still very strong and that's what I need tae tell [doctor's name] tomorrow

An important factor that appears to influence the individual's decision to remain abstinent is the ability to identify and implement conditional choices:

P1: Ach, no, it's just I mean, I'm happy being here. So, I mean, I know that if I go on the drink again that's, well, that could mean not living here, living somewhere else...

P7: So it is and, and people says tae me what would you rather choose, will you choose alcohol or choose life?

The harmful effects of alcohol

The decisions that are made for abstinence need to be supported by relevant information and evidence in order for participants to continue abstaining. This became apparent when participants discussed the harmful effects of alcohol and how these fell into three main categories; physical effects, social effects and the realities of being alcohol dependent. Interestingly, this was one of the very few categories where participants discussed past issues.

The physical difficulties experienced were multifarious, but it was clear that a physical effect was felt by all participants:

P6: It was only a couple ae, couple ae lagers or something, shandy lagers or and I was, I smoked at the time and I had nae lighter and ma lighter had ran out and something like that, I took a light off the gas fire and just as I've took it, I had ma dressing goon on, ma nightdress and the … nightdress just went up in flames. Oh I was in hospital fur that tae, aw roon ma chest, aw doon here and on ma legs. That was 3 month, 2 month in hospital wi' that.

P8: It's the body that needs the drink, canny dae withoot it, know what I mean?

P7: I was living there maself, so I was and I wisnae eating.

There were also significant social effects:

> *P3:* .....Got a divorce, eh, I lost my house, my car, every stick of furniture and all I got was a wee bag of claethes – bye bye, you're on your own….. That was about it, you know. That was it.....
>
> *P9:* but I got caught drinking so they sacked me

And finally, the realities of being alcohol dependent:

> *P9:* See the, the person I was, the person I was was an alcoholic and I drunk alcohol every single day. Every single minute I had alcohol
> *R:* Okay
> *P9:* So ma body ended up depending on the alcohol.

These difficulties were used as arguments against relapse. They, in essence, were the fuel that enabled participants to adapt and maintain abstinence at difficult times, and to remember why it was necessary to continue their abstinence when life became less challenging in terms of alcohol dependence.

Being supported through ARBD

The main themes developed within this category interact and feed into all the other categories. There was a clear collaborative relationship between individuals and their specialist support mechanisms, which provided the skills, support and growth necessary for participants to activate the processes which underpin the transformation model – specifically empowerment, adaptation and transformation.

The main themes developed within this category were: 1) "*The 'essentialness' of specialist services*", and 2) "*Improving quality of life*".

The 'essentialness' of specialist services

Participants found the support of specialist services invaluable throughout the whole recovery process. They described feeling understood, helped and connected to services, which for many were described as being life-saving, and which could not have been managed on their own:

> *P3:* I'd have died from drinking, put it that way..... Totally, I would have drunk myself to death, you know. I know it sort of sounds crazy, but it's, you know..

> *P9:* But I didnae realise this. It was working wi' ARBD team who basically told me what was, what was wrong wi' me and I was quite happy wi' that because I can go oot and say tae ma people noo.

There was also acknowledgment of the variability of services:

> *P4:* I was wi' them for 7 and a hauf year in [location]. But you were allowed to drink...

> *P6:* Aye, I had that beautiful [place], but I was going oot taking a drink.
> *R:* Right, because it wasn't a, a non-drinking place?
> *P6:* Uh-huh, that's how [my support worker] got me in here

Improving quality of life

There was also improvement in the quality of life of participants. They felt connected to others through peer-support groups; their condition and experiences felt normalised; and for many, this seemed to represent a significant support to their journey through recovery:

P9: I couldnae dae anything at aw but fae I started working wi' your people it's, it's helped me big time because I'm working wi' other people who are in the same boat as me

P10: And then there's like see because they're aboot 30 and the m, all the people they all sit and talk about other, maybe you're say something, that's happened to me. I know whit I've done, you know, I done and they, I went through that and you have a discussion and then if you come across that you know what to do or who to go and see, see how you did do it so

A sense of belonging appeared to present a significant protective factor for individuals in their recovery. As alcohol dependence is often accompanied by isolation, and a sense of being excluded, the use of peer support in recovery acted as an antidote to the negative emotional effects of such isolation:

P6: They canny really understand it tae they go through it.

P9: It's made a big difference. See talking tae people who are the same as yourself or worse than yourself

Creating a valuable life

Participants reported a significant difference in the way that they lived now, with hope, happiness and a sense of achievement winding its way through their discourse. These individuals described valuing themselves and their lives.

The main themes developed within this category were 1) "*Changing and adapting for recovery*" and 2) "*Planning for a positive future*".

Changing and adapting for recovery

Having taken ownership of their condition, participants worked towards creating a valuable life, allowing the development of skills, not all of which were related to ARBD:

> *P3:* Aye – about trial and error. But that wasn't for me at all! I prefer, you know, to use my hands and whatever, you know. The courses I done were excellent. I glassed and framed every one of them certificates as well – just paid for the materials.

> *P8:* I was all over the place. It takes ye a wee while tae build in to yourself your own confidence.....and if I've, work wi' in ma structured life I'm quite happy.

Importantly, participants were all very aware of the improvements that had been made and were still occurring:

> *P3:* Aye – I'm getting there you know, slow but sure, you know.

> *P6:* A big difference from me now fae being in here, a different person aw the gether noo.

> *P9:* Eh fae I've been working wi' alcohol services and the ARDB, that has aw started changing because I'm starting tae remember things and I'm starting tae realise whit things are priority

Planning for a positive future

Part of creating a valuable life was about making plans for the future. These included repairing fractured relationships damaged as a result of alcohol and its consequences:

P7: So I've told the staff, told everybody, just like know I've had the big 50, I'd like tae move on, so I dae. So know, I want tae start, honest tae god I want tae start a brand new life

P3: And ... get to see my daughter, which will be kind of strange for her as well you know, cos I haven't seen her for 15-16, year.

P9: Thought aw maself only. Noo it, I've seen ma, ma, ma chance to, as I say, reinvent maself.

In addition, a wish to live 'better' came through in the interviews. Participants provided lots of examples of wanting to live a better life; for example becoming a better person, improving aspects of themselves and learning from mistakes:

P6: I want tae get back tae maself hen, I want tae get ma [self] back, no the one no the one that was drinking.

P7: So I dae cause I'm determined tae start a brand new life.

Finally, there was evidence regarding living well, feeling happy, feeling blessed, feeling that their lives had turned around, and an absolute certainty of not wanting to go back down the same road:

P7: Hmmm, well important tae me so it is eh god [sigh] eh, still hope tae, I get fit and healthy so I do

P1: Ach, no, it's just I mean, I'm happy being here. So, I mean, I know that if I go on the drink again that's, well, that could mean not living here, living somewhere else...

P9: I'm happy, very happy

This category also hinges on the need to adapt, to be able to make significant changes in their lives in order to not just manage ARBD, but to live a successful and valued life.

Discussion

Results of this analysis of 10 interviews with people diagnosed with ARBD suggest an experience of "transformation through adaptation". This process allowed the participants in this study to move from a position of being physically and cognitively unwell, towards a life which they found to be positive and valuable. It is the process of adaptation which is hypothesised to be crucial to successful recovery from ARBD: not necessarily in terms of the 'repair' of cognitive functioning (although this does occur), but in terms of quality of life and reintegration into community/society.

There is a significant body of research on the subject of adaptation and adjustment in health conditions (e.g. de Ridder et al., 2008; Sharpe & Curran, 2006). The literature raises issues relating to models of adjustment (Walker, Jackson & Littlejohn, 2004), as well as the roles that self-efficacy (Rottman, Dalton, Christensen, Frederiksen & Johansen, 2010) and psychological adjustment (de Ridder et al., 2008) play. As in many areas of health, models are moving away from medical approaches to more holistic biopsychosocial approaches. One such model, proposed by Samson and Siam (2008), highlights the importance of understanding how individuals adapt to their conditions over the long-term. It is hoped that the results of this present study go some way to informing this area of research with regards ARBD.

There is much to overcome at the point of diagnosis of ARBD, as is the case with other serious diagnoses (e.g. Anson & Ponsford, 2006). There is the reality that continued

drinking may lead to severe cognitive impairment, or death (Shield, Parry & Rehm, 2013); there is the 'enforced' decision to become abstinent, which is a challenging process without the added difficulty of cognitive impairment, physical health difficulties and a diagnosis of a chronic health condition; there is the change in personal circumstances, e.g. moving to different accommodation, being away from family; and all of this is often done within a framework lacking in information. This lack of appropriate information has been identified in research with other diagnoses such as type 2 diabetes (Peel, Parry, Douglas & Lawton, 2004) and was highlighted as a something that was missing for the participants within the present study. Hepworth, Harrison and James (2002) found that people being diagnosed with Multiple Sclerosis had very specific requirements for how information was presented that catered for the cognitive and physiological condition of the patient and made a distinction between information needs at diagnosis and long-term information needs. Participants described their diagnosis as a pivot point, a point at which changes are made and individuals start to progress through the model postulated within this study. This pivot point has been identified in other research relating to diagnosis of health conditions such as HIV (Baumgartner & David, 2009).

During the stage of diagnosis, it appears that individuals begin to make helpful and adaptive choices which allow them to start moving forwards. In relation to the model, it begins moving them towards a point where they can begin to take ownership of their difficulties. After diagnosis of a chronic condition such as ARBD, patients are often presented with novel situations that challenge their existing coping strategies (or lack thereof). As a result, they need to find new ways of coping to adapt to their new circumstances (de Ridder et al., 2008). This was something that many of the participants interviewed in this study initially struggled with, particularly with regards to memory. The participants in this study were assisted to employ a number of memory-supporting strategies

such as using whiteboards, diaries and calendars, as well as learning the benefits of routine and repetition. These are strategies that have been successfully employed in both dementia (Gibson et al., 2014) and brain injury (Evans, Wilson, Needham & Brentnall, 2003). There is also a developing body of evidence regarding the benefits of these strategies in ARBD as shown by the work of Wilson et al. (2012) regarding psycho-social rehabilitation in the community.

This connection to community is something that is described by the process of reintegration. While recovery is often viewed as the pinnacle of success for patients with alcohol dependence, its lack of definition makes it a difficult goal to quantify (White, 2007). While some definitions of recovery also allude to improved quality of life (Laudet, 2011), there are few guidelines about what this is, and how it should be achieved. Reintegration specifically considers the aspects of community living that can lead to positive and contributing lives after illness or addiction, however little attention is paid to the role of physical recovery (Wood-Dauphinee & Williams, 1987; Dijkers, 1998). Part of the path to transformation described in this model is likely to have been achieved by a combination of recovery and reintegration. Both of these processes require significant changes. The changes seen by the participants in this study included: abstinence; removal of self from risky situations, for example no longer seeing friends who drink; development of new routines and skills, for example using memory-aids and routine; and reintegrating into a community, in most instances for these participants, one created by people with ARBD.

Leading on from this reintegration into community, there is a strong body of evidence within substance misuse regarding the benefits of support. Moos (2007) identified specific components of effective treatment programs which included: support, goal direction and structure; an emphasis on rewards that compete with substance use; a focus on abstinence-oriented norms and models; and attempts to develop self-efficacy and coping skills. Moos'

study (2007) further supports the findings of the current study as both help to identify areas that supporting professionals can focus on. Areas identified in this present study are the support required: during the diagnostic period, particularly in relation to providing information; to accept and understand the condition, and assistance with techniques and strategies required to improve and adapt to cognitive (and sometimes physical) impairments; to become involved in fulfilling and absorbing activities that improve quality of life; as well as continual ongoing support for maintaining abstinence. As is emphasised by the model, the support provided by a variety of services weaves its way throughout the ARBD journey and many of the stages would likely not be possible without this support. Participants certainly understood the value of the support they had received when they described it in terms of "essentialness".

Alcohol dependence is often described as a chronically relapsing condition (e.g. Stockwell, 1999) with periods of both abstinence and active drinking. Whether it was a function of the support that they were receiving, the seriousness of the condition, or individual factors, the participants in this study were able to manage their abstinence, apparently by keeping a 'focus' on it at all times. The focus changed from that of cravings and relapse management to one using factors from their improved circumstances as reminders of what they might lose. The process of abstinence highlights the adaptability required within this model: the many changes required to move from drinking to sobriety; the adaptations required to manage cravings; and finally the changing core focus on abstinence itself.

While there are currently few models to describe the processes associated with ARBD, the work by Wilson et al. (2012) provides a rehabilitation framework for intervention. Their research suggests that services should rely on person-centred care, close follow-up and collaborative work with community agencies. This study expands on this by

incorporating the voice of those living with ARBD and developing a model that describes the elements that may be responsible for a successful progression through ARBD towards living a valuable life. It is posited that these two models, used in parallel, may help to create services that successfully allow patients to negotiate their way through the process of ARBD.

Implications for clinical practice

A number of key issues emerged in this study. Firstly, it would seem that specialist support services (those appropriately trained and informed regarding both substance misuse and ARBD) are vital to the process of recovery. As there are currently only four specialist services in the UK (Liverpool, Fife, Glasgow and Edinburgh), and the best evidence indicates that 0.5% of the UK adult population will have neuropsychological changes as a result of excessive alcohol misuse (Royal College of Psychiatrists, 2014), there is a clear need for health boards and government bodies to look at service provision both locally and nationally. This study reinforces the necessity for these types of services. According to this model, these services play an essential role in the process of transformation, by supporting participants in the identification and implementation of the adaptations that are necessary for transformation.

This study's proposed model also provides a tentative template for areas to focus on during treatment of ARBD as highlighted by people with lived experience. Clearly, relapse prevention is a vital element of any alcohol treatment (Scottish Intercollegiate Guidelines Network, 2003), however there is the danger that when dealing with the more severe aspects of ARBD that the alcohol treatment element of the condition can be neglected. This model provides a reminder of the necessity to support the abstinence of patients. Similarly, there needs to be recognition of the adaptations that are required for alcohol treatment programs to be effective when cognitive dysfunction is present (e.g. Bates, Bowden & Barry, 2002; Bates, Buckman & Nguyen, 2013). In ARBD, the areas of cognitive deficits most often seen – such

as memory, attention, planning, judgement and processing of new information – are those that are required for successful engagement in treatment programmes. In other words, treatment needs to be tailor-made to the individual's specific needs, and may need to focus on cognitive remediation or rehabilitation (Bates et al., 2002) before more specific alcohol treatment is carried out.

Information is a vital part of any diagnosis (see e.g. Hepworth et al., 2002) and for the participants in this study, this was something they lacked. There are multiple factors at play here, the knowledge of diagnosing staff, GPs and other health professionals, as well as the stigma associated with a diagnosis of ARBD (Wilson, 2011; Cox et al., 2004). Patients are given information at a time when their cognitive functioning is severely compromised, and as such, there is a responsibility on health professionals to provide information in a form that can be both understood and retained. Professionals can help by being properly informed about the symptoms, impact and prognosis of ARBD, and can further assist by raising public and professional awareness and by providing ongoing education and support to patients (Aminzadeh, Byszewski, Molnar & Eisner, 2007). Advice and guidance on these elements should be sought from services who already manage such difficulties, such as in acquired brain injury services.

Adaptation to ARBD is the vital element within this model and there is a responsibility on health services to assist in this process. There are a number of models of adaptation/adjustment to chronic illness – e.g. the model of cognitive adaptation; the personality model; and the stress and coping model (de Ridder et al., 2008) – and these should be considered (at least until further research is done with ARBD patients) as a source of support for both professionals and patients.

Future research

This model theorises that adaptations can lead to transformation for those diagnosed with ARBD. What is not clear at present is the mechanism that is required for this. Was it the actual changes that were made by these participants that facilitated their transformation; or was it some measure of 'adaptability' that the participants possessed that enabled them to make the appropriate adaptations? It would be interesting to investigate this issue further. If it is the changes themselves that are responsible for the transformation, then a specific treatment protocol can be developed to incorporate the necessary steps for successful treatment. If success is due to individual 'adaptability' resources then firstly, a way of assessing this needs to be developed; and secondly, further research needs to be carried out in order to determine how to increase this in those with limited capacity for this 'adaptability'.

Finally, while it is possible that much of the existing health research evidence base discussed previously is applicable to the diagnosis of ARBD, it is only through research on this group specifically that we can be certain.

Limitations

This study evolved into a story of success. The theory that emerged was one connected to the successful management of living with ARBD, of patients transforming themselves and their lives as a result of the processes at play. It is important to note that the participants interviewed were abstinent, physically well (barring some mobility issues), living in safe and supported accommodation and supported in their sobriety and ARBD recovery by specialist teams. It is likely that if it were possible to interview participants with ARBD who were still drinking, who were not connected to services and did not have the other physical supports in place, then the theory generated would be very different. While this theory therefore does not

relate to all people with ARBD, it raises some interesting and important elements regarding how participants can be supported to successfully manage a diagnosis of ARBD.

A central tenet of grounded theory is the use of theoretical sampling in order to develop theory and achieve saturation of categories. As the population being studied is one that is hard to reach and the available sample was small, theoretical saturation was pursued through the adaptation and tailoring of the interview process as the study developed (Birks & Mills, 2011). While true saturation may not have been achieved as a result, it was felt that theoretical sufficiency was reached (Dey, 1999).

As participants opted in to the study, there is the possibility for bias in that those who chose to participate may have been those who felt that they had had positive experiences and wished to share these. This leaves the possibility that those patients who did not wish to participate had less positive experiences. Also, the participants in this study were all Scottish and White, which may limit the generalisability of the findings beyond this cultural group.

Finally, a supporting perspective from the specialist support services involved in the ARBD service was not sought in this study due to time constraints. It is likely that their perspective would have added a further dimension to this study, particularly regarding the methods and working practices that appear to have been so successful for this participant group.

Summary and conclusions

The results of this study provide a tentative model for the process by which patients can successfully navigate the journey of being diagnosed with ARBD and move towards recovery and transformation. This research highlights the importance of the role that adaptation plays in the successful negotiation of a diagnosis of ARBD, and proposes a series of categories ("*Being diagnosed with ARBD*", "*Taking ownership of life with ARBD*";, "*Creating a*

valuable life";, "*Being supported through ARBD*" and "*Focusing on abstinence*") that can be used as a framework to identify and support the changes that are necessary for recovery and reintegration. The value in this study is that the results are directly attributable to individuals who have been diagnosed, and are now successfully living, with ARBD.

There is clearly a significant need for research within this field, and considering the potential for recovery within this population, research in this area should be prioritised. The following areas should be considered:

- Adaptation appears to be the core factor within this study that allowed participants to 'transform'. However, further research is required to determine what allowed these adaptations. Was it related to personal factors such as resilience, motivation or recovery capital? Or was it related to external factors such as specialist support, good nutrition and safe accommodation? This needs to be clarified with future research.
- An important area that was not covered by the data within this study was the story of the patients who did not become abstinent and did not engage in services when diagnosed with ARBD. It may be possible to determine differences in, for example, motivation, self-efficacy or severity of alcohol dependence in order to help identify the 'core' factors which allowed the participants within this present study to be successful. Identifying such factors could then be used to develop treatment programmes to help develop these skills in ADP.
- It is possible that there is an 'inverse' model for those people with ARBD who do not follow this path. It is likely that a patient with ARBD who continues to drink will find their situation becomes progressively worse as their cognitive

functions decline, their nutrition intake suffers and their living conditions deteriorate; leading to a very poor prognosis. Hypothesising about this inverse model highlights the value and importance of helping this population to achieve the transformation, rather than the alternative.

People diagnosed with ARBD have enormous potential to recover and return to living a positive and fulfilling life, and there is therefore a responsibility upon researchers and clinicians to develop treatment programmes and services that support this potential. It is hoped that this study provides a springboard for such future developments.

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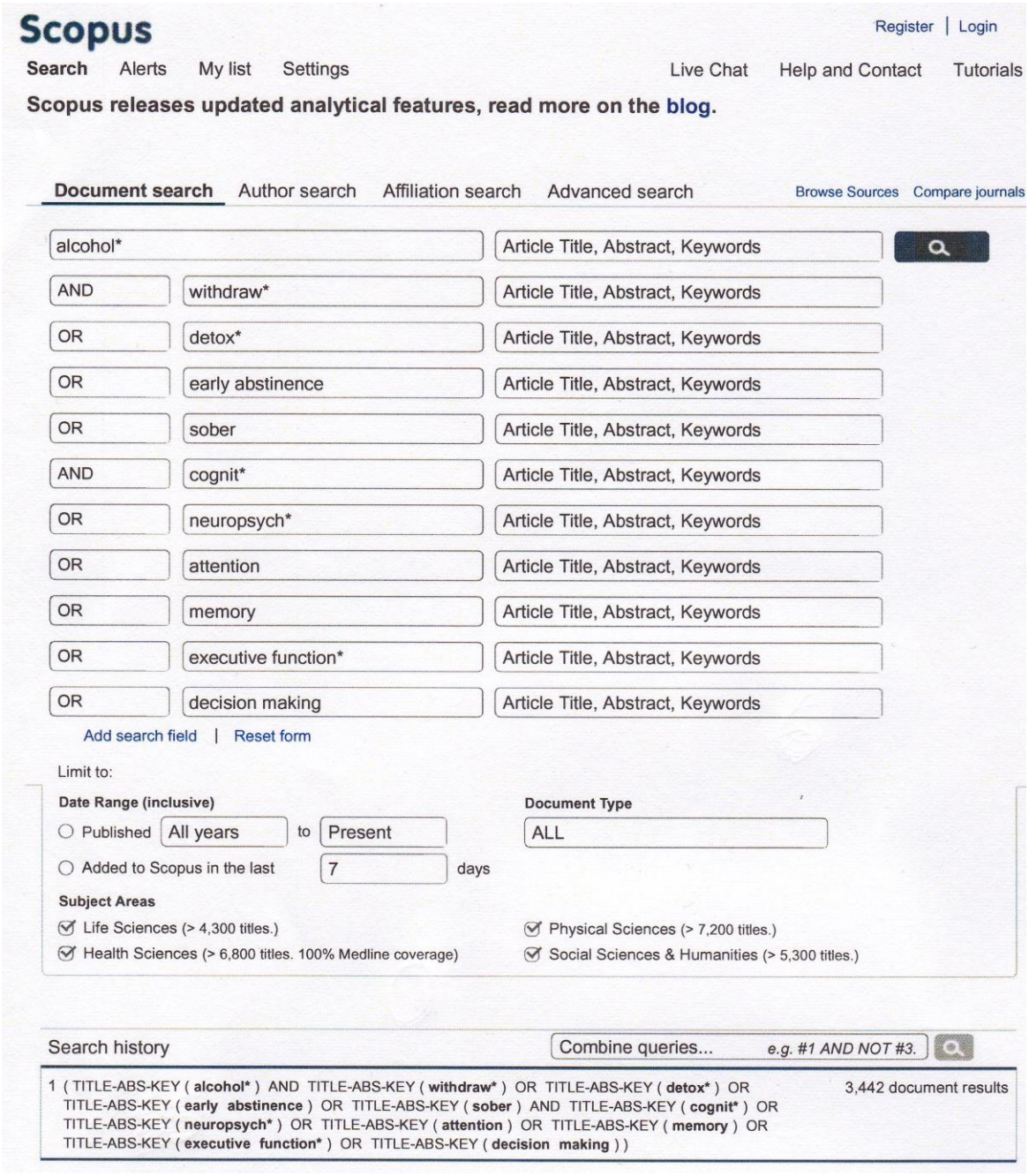
APPENDICES

Appendix 1 – Scopus Search



Appendix 2 – Quality Assessment Form

Quality Assessment Criteria			
Author:			
Year:			
Title:			
Study			
1. Study addresses an appropriate question with aims clearly defined		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
Selection of subjects		**Subtotal**	
2. The case and controls were taken from comparable populations		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
3. The same exclusion criteria are used for both cases and controls		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
4. Alcohol dependence is measured in a standard, valid and reliable way		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
Assessment and measures		**Subtotal**	
5. Outcomes and potential confounders are clearly defined		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
6. Outcome measures are relevant and appropriate		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
7. Outcome measures are valid, reliable and standardised		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	

		Not applicable (0 points)	
Analysis and Results		**Subtotal**	
8. Study is adequately powered		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
9. Appropriate analysis for outcome measures used and p values and effect sizes reported where appropriate		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
10. Confidence intervals are reported		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
Discussion		**Subtotal**	
11. Results are summarised with reference to study objectives		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
12. Limitations are addressed		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
13. Interpretation of the results are cautious and considering objectives, limitations, analyses and relevant evidence		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
14. Generalisability is addressed		Well covered (2 points)	
		Adequately addressed (1 point)	
		Poorly addressed (0 points)	
		Not addressed (0 points)	
		Not reported (0 points)	
		Not applicable (0 points)	
		Subtotal	
Reviewer:		**Total score**	

Appendix 3 – Summary of Neuropsychological Measures

Memory Screening Test (MST; Cocks, 1992)
The Memory Screening Test (MST) was used to examine both verbal and visual memory in the study by Taylor, McGown and Anson (1997). The MST examines the effect of interference on subjects' ability to remember in three modalities. Word recall involves the recall of three words after exposure to a similar interference set. Sentence recall involved recall of a sentence after interference from another similar sentence. Figure recall involved copy and recall from the Benton Visual Retention Test, after being given an alternative figure to copy and remember as interference.

Auditory-Verbal Learning Test (AVLT; Rey, 1964; Schmidt, 1996)
Verbal memory is measured by a five trial presentation of a 15 word list (list A), a single presentation of an interference list (list B), two post-interference recall trials – immediate and delayed – and recognition of the target words presented with distracters.

Wechsler Memory Scale – Revised (WMS-R; Wechsler, 1987)
Demir et al. (2002) reported using a "modified" version of the WMS-R to assess verbal and visual components of memory. The tests included were figural (described as figurative) memory, logical memory, visual paired associates, verbal paired associates, visual reproduction, digit span, and visual memory span. Figural memory is an immediate recognition test of abstract designs; logical memory incorporates immediate and delayed (30 minute) recall of two stories; visual paired associates pairs abstract line drawings with colours and colour point response required, immediate and delayed conditions are tested; verbal paired associates involves learning eight word pairs (four "easy" and four "hard" associations) tested by immediate and delay (30 minute) recall); visual reproduction assesses immediate and delayed recall for a visual drawing task; digit span measures forward span, of three to a possible eight digits, and backward span from two to seven digits; finally, visual memory span measures the ability to reproduce the spatial pattern of tapping sequences on an array of blocks, forward and reversed.

California Verbal Learning Test (CVLT; Delis, Kramer, Kaplan & Ober,1987)
Hildebrandt et al. (2004) used the CVLT. This test consists of learning 16 words belonging to one of four categories (fruits, herbs and spices, clothing and tools). Following five trials with the original list, an interference list is read. Two short delay recalls are obtained, the first is free recall, where the subject recalls as many of the words as possible, the second, the subject is asked to recall items in categories. There is a delayed recall after 20 minutes (using both free and cued recall). This is followed by a recognition task.

Verbal Learning and Memory Test (VLMT; Helmstaedtder et al., 2001)
The VLMT was used by Daig et al. (2012) and Wollenweber et al. (2014). This is an adapted German version of the Rey Auditory Verbal Learning Test. It consists of a learning list and a distraction list. The learning list is read over five trials, with the distraction list being presented after the fifth trial. The subjects are then asked to recall the distraction list, followed by the learning list. Delayed recall follows after 30 minutes.

Benton Visual Retention Test (BVRT; Benton, 1992)
Emmerson et al. (1988), Mann et al. (1999) and Loeber et al. (2009) used the BVRT. The BVRT is a test used to assess visual perception, memory and constructive abilities. Ten

images are presented one at a time for 10s. After each presentation, subjects are asked to draw the image from memory.

Figure Position Test (FPT; Moriyama et al., 2006)
Moriyama et al (2006) used the FPT. This test involved memorising two to four figures (e.g. a triangle and a square) together with their positions among six possible configurations. Subjects were instructed to recall the figures and their positions after 15 second intervals. The summed tie for completion was calculated. This test is thought to reflect non-verbal short-term memory or spatial working memory.

Rey-Osterrieth Complex Figure Test (R-OCFT; Osterrieth, 1944; Rey, 1941)
The R-OCFT was used by Daig et al. (2010). It is used to assess visuo-spatial constructional ability and visual memory. Subjects are asked to copy a figure onto a blank sheet of paper; three minutes after completion, they are asked to reproduce the figure from memory (immediate recall); thirty minutes later, they are asked again to reproduce the figure as accurately as possible (delayed recall).

Free and Cued Selective Reminding Test (FCSRT; Grober & Buschke 1987; der Linden and GREMEM group, 2004)
The FCSRT, used by Le Berre et al, (2012) and Ritz et al. (2014), uses category cues at both acquisition and retrieval in an attempt to ensure semantic encoding and enhance recall. The subject is required to search a card containing line drawings of four objects and identify the one that belongs to a category named by the examiner. Each of the 16 items to be learned appears on one of four cards. After the item on the card is correctly identified, the card is removed and immediate recall of the four items is tested by cueing with the category prompt. The subject is corrected for any errors. Additional items are presented four at a time in the same manner. Four recall trials are then obtained; free recall is followed by cued recall if items are not spontaneously reported. Missed items are presented again with their cues.

Spondee Test (Pitel et al., 2007a)
This test (used by Pitel et al., 2007a; Le Berre et al., 2010; Le Berre et al., 2012) consists of two lists of 16 words belonging to different categories. The words in the first were encoded spontaneously according to strategies that subjects employed on their own. Subjects had to point to words as they were read out by the examiner. The words in the second list were deeply encoded in a semantic mode – subjects had to point to words in response to their semantic category. A free recall test, a semantic cued recall test and a recognition task were then carried out for each list. During the recognition phase, subjects were asked to specify their state of consciousness for each correctly recognised word using the Remember/Know paradigm. "R" answers signified that subjects remembered the learning episode and were able to provide details about it, so refers to conscious recollection concept. "K" answers indicated that subjects knew that they had learned the information but were unable to give details about the learning episode; it corresponds to the familiarity concept. The average of percentages of R answers for spontaneous and deep conditions was used for dependent variable. Two other sub-scores were also used to preferentially reflect encoding versus retrieval capacity 1) the recognition score after superficial encoding (1^{st} list) is assumed to be more dependent on encoding ability because retrieval is facilitated, while 2) the free recall after deep encoding (2^{nd} list) is assumed to mainly reflect retrieval ability because encoding is reinforced. Le Berre et al. 2012 used this method.

Appendix 4 – Ethics Paperwork

Lothian NHS Board

South East Scotland Research Ethics Committee 02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 465 5789

www.nhslothian.scot.nhs.uk

Date 26 July 2012
Your Ref
Our Ref

Enquiries to: Joyce Clearie
Extension: 35674
Direct Line: 0131 465 5674
Email: Joyce.Clearie@nhslothian.scot.nhs.uk

26 July 2012

Mrs Heather Simpson
Clinical Psychologist in Training
NHS Lothian
Substance Misuse Directorate
Spittal Street Centre
Edinburgh
EH3 9DU

Dear Mrs Simpson

Study title:	**The patient experience of Alcohol Related Brain Damage – a Grounded Theory Approach**
REC reference:	**12/SS/0122**
Protocol number:	**12/SS/0122**

Thank you for your recent letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by the chair on behalf of the REC.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

NHS
Lothian

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
GP/Consultant Information Sheets	1.0	16 May 2012
Interview Schedules/Topic Guides	1.0 Focus Group Questions v1.0	26 June 2012
Investigator CV	CI Simpson	
Investigator CV	supervisor Rourke	
Investigator CV	Supervisor Quayle	
Other: Thesis Proposal	1.0	23 April 2012
Participant Consent Form: PCF	1.1	25 July 2012
Participant Information Sheet: PIS	1.1	25 July 2012
Participant Information Sheet: PIS Staff	1.1 Staff	25 July 2012
Protocol	1.1	25 July 2012
REC application		20 June 2012

NHS
Lothian

Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/SS/0122	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Mr Thomas Russell
Chair

Email: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments [if final opinion was confirmed was given at a meeting]*

Research & Development Directorate
NHS Greater Glasgow and Clyde
The Tennent Institute
WIG, 38 Church Street
Glasgow
G11 6NT

NHS
Greater Glasgow and Clyde

Mrs Heather Simpson
Trainee Clinical Psychologist
Substance Misuse Directorate
Psychology Department
Spittal Street Centre
22-24 Spittal Street
Edinburgh EH3 9DU

Date 01 August 2012
Our Ref GN12AL319

Direct Line 0141 211 6208
Fax 0141 211 2811
Email: Erica.packard@ggc.nhs.co.uk

Dear Mrs Simpson,

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. This letter confirms your right of access to conduct research through **NHS Greater Glasgow and Clyde** for the purpose and on the terms and conditions set out below. This right of access commences on **1st August 2012** and ends on **1st November 2013** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to NHS Greater Glasgow and Clyde premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through NHS Greater Glasgow and Clyde, you will remain accountable to your employer **NHS Lothian**.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with NHS Greater Glasgow and Clyde policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with NHS Greater Glasgow and Clyde in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while NHS Greater Glasgow and Clyde premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as

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Greater Glasgow and Clyde

is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

NHS Greater Glasgow and Clyde will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

E Packard

Dr Erica Packard
Research Co-ordinator

NHS
Greater Glasgow and Clyde

Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

1 August 2012

Dr Jenny Svanberg
Chartered Clinical Psychologist
Alcohol Related Brain Damage Team
86 Millbrae Road
Glasgow G42 9UG

NHS GG&C Board Approval

Dear Dr Svanberg,

Study Title:	**The patient experience of Alcohol Related Brain Damage – a Grounded Theory Approach**
Principal Investigator:	**Dr Jenny Svanberg**
GG&C HB site	**Alcohol Related Brain Damage Team**
Sponsor	**University of Edinburgh & NHS Lothian**
R&D reference:	**GN12AL319**
REC reference:	**12/SS/0122**
Protocol no: (including version and date)	**V1.1; 25/07/12**

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information relating to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

NHS
Greater Glasgow and Clyde

2. **For all studies** the following information is required during their lifespan.
   a. Recruitment Numbers on a monthly basis
   b. Any change of staff named on the original SSI form
   c. Any amendments – Substantial or Non Substantial
   d. Notification of Trial/study end including final recruitment figures
   e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

EPackard

Dr Erica Packard
Research Co-ordinator

Appendix 5 – Participant Information and Consent Forms

THE UNIVERSITY
of EDINBURGH

Participant Information Sheet

Study Title: The patient experience of Alcohol Related Brain Damage – a Grounded Theory Approach

You are being invited to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to discuss it with somebody if you wish. Please take time to decide whether you wish to participate.

What is the research about?
The study aims to develop a grounded theory based on the patient experience of Alcohol Related Brain Damage (ARBD). This will be done through the use of interviews which will identify the main themes and issues which are central to people living with ARBD. It is hoped that this information will lead to the development of shared understanding and meaning which can be used to enhance services.

Grounded theory is a method used in research to explore individuals' experiences in the context of the worlds in which they live. The questions that the researcher repeatedly asks in grounded theory are *"what's going on?"*, and *"what is the participants' main experience and how do they deal with it?"*.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and you do not have to give a reason. This will not affect the type or standard of care you receive.

What would be involved if I choose to take part?
If you choose to take part in this study, you will be asked to take part in a focus group and/or an individual interview where we will discuss your experiences of ARBD. You will be welcome to ask questions throughout the session and will also be free to withdraw at any time

should you choose to. The focus group should take no longer than 90 minutes and the interview should take no longer than 60 minutes.

The interview/focus group will consist of general discussion which is likely to begin with a question such as: *"To begin, I would like you to describe what stands out most for you in your experience of being diagnosed with ARBD"*. What is discussed will depend on what is important for you – I may ask for additional information by asking a question such as *"can you tell me a bit more about that"*.

Towards the end of my research, I will arrange an additional focus group/group discussion. This will be to check that the information gathered already is relevant to other people with ARBD and to answer any outstanding questions. In this group, you may be asked questions such as "do you feel being diagnosed with ARBD has been pivotal to your recovery?". You will only be invited to attend one focus group.

All interviews and focus groups will be recorded. These recordings will be typed up by a transcription service that specialises in this. Your names will not be included on the recordings. The original recording will then be destroyed.

Interviews will take place either within the ARBD service, or, where appropriate and agreed, in your own home. Any interviews will be tied in to visits that you would normally make to the ARBD service; therefore no additional travel will be required.

What are the possible benefits of taking part?
I cannot promise this study will help you directly, but the information I collect from this study may help us better understand the experience of ARBD.

Are there any risks of taking part?
It is possible that talking about your experience of ARBD may bring up things that are difficult or upsetting for you. If this were to happen, I would contact a key member of the ARBD team so that some additional support could be arranged through the team.

What will happen to the results of the study?
The findings of the study will be written up as part of my doctoral degree in Clinical Psychology. I also hope to publish the results of the study in a specialist mental health journal. No one participating in the study will be able to be identified in the results or publications arising from this research.

If you are interested, I can arrange for a summary of the results to be sent to you after the study is complete.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by NHS Lothian Research Ethics Committee.

Will my taking part in the study be kept confidential?

Yes. All information that you provide will be kept confidential according to NHS Guidelines.

Within the focus groups, information will be discussed in front of others. The same rules regarding confidentiality will apply as for the groups that you attend.

Any data relating to the study, including recordings, will be stored in a secure, locked environment.

During the study, authorised individuals from Edinburgh University, regulatory authorities or from NHS Lothian may wish to view data collected in order to monitor or audit the study.

If you wish we will contact your GP advising them of your participation in this study.

Who can I speak to about the study?
I would like you to have plenty of time to consider whether you want to take part, however if I have not received consent within 14 days, I will assume that you do not wish to participate and I will not contact you again.

If you would like further information about the study, or you would like to discuss any concerns that may have been raised for you, please feel free to contact me on 07800 955 938; heather.simpson@nhslothian.scot.nhs.uk. You can also speak to your ARBD worker if you have any queries or concerns.

If you would prefer to speak to someone who is independent of the study you may also contact Ms Eunice Reed, Lead Clinical Psychologist, Substance Misuse Directorate, NHS Lothian. She is an independent contact who is not associated with either this study or the department in which it is being run. You can contact her on 0131 537 8300.

What if I am unhappy with any part of the study?
If you are unhappy about any aspect of the study and wish to make a complaint, please contact NHS Greater Glasgow and Clyde:
phone: 0141 201 4500
e-mail: complaints@ggc.scot.nhs.uk

Thank you for taking the time to read this information sheet and for considering whether you would like to take part.

Yours sincerely

Heather Simpson
Clinical Psychologist in Training
Tel: 07800 955 938
Email: heather.simpson@nhslothian.scot.nhs.uk

CONSENT FORM

Title of Project: The patient experience of Alcohol Related Brain Damage – a Grounded Theory Approach

Name of Researcher: Heather Simpson

Patient Identification Number: _____

		Please initial box
1.	I confirm that I have read and understand the information sheet dated 05/02/2014 (version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3.	I understand that relevant sections of my medical notes and data collected during the study may be looked at by authorised individuals from Edinburgh University, regulatory authorities or from NHS Greater Glasgow and Clyde. Where it is relevant to my taking part in this research, I give permission for these individuals to have access to my records.	☐
4.	I agree to my GP being informed of my participation in the study.	☐
5.	I agree to take part in the above study.	☐

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 6 – Author Guidelines Drug and Alcohol Dependence

Introduction

Drug and Alcohol Dependence is an international journal devoted to publishing original research, scholarly reviews, commentaries, and policy analyses in the area of drug, alcohol and tobacco use and dependence. It is sponsored by the College on Problems of Drug Dependence (CPDD), the oldest scientific organization in the United States concerned with research on addiction. The goal of its editors is to promote mutual understanding of the many facets of drug abuse to the benefit of all investigators involved in drug and alcohol research, and to facilitate the transfer of scientific findings to successful treatment and prevention practices. Drug and Alcohol Dependence is currently being distributed to all the members of CPDD.

Types of paper

1) Full-length Reports reporting original results of research within the field of drug, alcohol and tobacco use and dependence. A Full-length Report typically should not exceed 4000 words (for the introduction, methods, results and discussion).

2) Review Articles of specialized topics within the scope of the journal. Typically, these are critical reviews of a field of research. A Review Article typically should not exceed 6000 words for the main body of the paper (i.e., excluding references, tables and figures). Review Articles that will be substantially longer than 6000 words should be discussed with the Editor-in-Chief prior to submission.

3) Short Communications reporting on research that has progressed to the stage where a preliminary publication is appropriate. The maximum length is 2000 words plus references and illustrations. There should be not more than 2 illustrations (figure or tables).

4) Commentaries express points of view on scientific matters or published papers. Typically, commentaries are solicited by the editors, but authors who wish to submit commentaries should contact the Editor-in-Chief to discuss the suitability of the proposed paper. A Commentary typically should not exceed 2000 words.

5) Registered Reports (click here for more details). These submissions undergo a two-phase review process in which study rationale and methodology are considered prior to the research being undertaken.

6) Other forms of papers. The journal does not publish letters to the editor, individual case studies or book reviews.

Before You Begin

Ethics in publishing

For information on Ethics in publishing and Ethical guidelines for journal publication see http://www.elsevier.com/publishingethics and http://www.elsevier.com/journal-authors/ethics.

Human and animal rights

If the work involves the use of animal or human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans http://www.wma.net/en/30publications/10policies/b3/index.html; EU Directive 2010/63/EU for animal experiments http://ec.europa.eu/environment/chemicals/lab_animals/legislation_en.htm; Uniform Requirements for manuscripts submitted to Biomedical journals http://www.icmje.org. Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.

Conflict of interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential conflicts of interest include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. See also http://www.elsevier.com/conflictsofinterest. Further information and an example of a Conflict of Interest form can be found at: http://help.elsevier.com/app/answers/detail/a_id/286/p/7923.

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Contributors

Each author is required to declare his or her individual contribution to the article: all authors must have materially participated in the research and/or article preparation, so roles for all authors should be described. The statement that all authors have approved the final article should be true and included in the disclosure.

Changes to authorship

This policy concerns the addition, deletion, or rearrangement of author names in the authorship of accepted manuscripts:
Before the accepted manuscript is published in an online issue: Requests to add or remove an author, or to rearrange the author names, must be sent to the Journal Manager from the

corresponding author of the accepted manuscript and must include: (a) the reason the name should be added or removed, or the author names rearranged and (b) written confirmation (e-mail, fax, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed. Requests that are not sent by the corresponding author will be forwarded by the Journal Manager to the corresponding author, who must follow the procedure as described above. Note that: (1) Journal Managers will inform the Journal Editors of any such requests and (2) publication of the accepted manuscript in an online issue is suspended until authorship has been agreed.
After the accepted manuscript is published in an online issue: Any requests to add, delete, or rearrange author names in an article published in an online issue will follow the same policies as noted above and result in a corrigendum.

Reporting clinical trials

Randomized controlled trials should be presented according to the CONSORT guidelines. At manuscript submission, authors must provide the CONSORT checklist accompanied by a flow diagram that illustrates the progress of patients through the trial, including recruitment, enrollment, randomization, withdrawal and completion, and a detailed description of the randomization procedure. The CONSORT checklist and template flow diagram can be found on http://www.consort-statement.org.

Registration of clinical trials

Registration in a public trials registry is a condition for publication of clinical trials in this journal in accordance with International Committee of Medical Journal Editors (ICMJE, http://www.icmje.org) recommendations. Trials must register at or before the onset of patient enrolment. The clinical trial registration number should be included at the end of the abstract of the article. A clinical trial is defined as any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects of health outcomes. Health-related interventions include any intervention used to modify a biomedical or health-related outcome (for example drugs, surgical procedures, devices, behavioural treatments, dietary interventions, and process-of-care changes). Health outcomes include any biomedical or health-related measures obtained in patients or participants, including pharmacokinetic measures and adverse events. Purely observational studies (those in which the assignment of the medical intervention is not at the discretion of the investigator) will not require registration.

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The four statements should not be numbered
Headings should be in bold
No white space between the heading and the text
Same font size as the references

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Please submit, with the manuscript, the names, addresses and e-mail addresses of a minimum of three potential referees. Note that the editor retains the sole right to decide whether or not the suggested reviewers are used.

Preparation

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.
To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Subdivision - numbered sections
Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Introduction
State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods
Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Results
Results should be clear and concise.

Discussion
This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Conclusions
The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Essential title page information

• **Title.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
• **Author names and affiliations.** Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
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Structured abstract

A structured abstract, by means of appropriate headings, should provide the context or

background for the research and should state its purpose, basic procedures (selection of study subjects or laboratory animals, observational and analytical methods), main findings (giving specific effect sizes and their statistical significance, if possible), and principal conclusions. It should emphasize new and important aspects of the study or observations.

Abstracts should be structured with specific sections describing the background, methods, results and conclusions with a maximum of 250 words.

Graphical abstract

A Graphical abstract is optional and should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership online. Authors must provide images that clearly represent the work described in the article. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. See http://www.elsevier.com/graphicalabstracts for examples.
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Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field at their first mention in the text. Ensure consistency of abbreviations throughout the article.

Units

Follow internationally accepted rules and conventions: use the international system of units (SI). If other units are mentioned, please give their equivalent in SI.

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many wordprocessors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.
Table footnotes
Indicate each footnote in a table with a superscript lowercase letter.

Artwork

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General points

• Make sure you use uniform lettering and sizing of your original artwork.
• Embed the used fonts if the application provides that option.
• Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
• Number the illustrations according to their sequence in the text.
• Use a logical naming convention for your artwork files.
• Provide captions to illustrations separately.
• Size the illustrations close to the desired dimensions of the printed version.
• Submit each illustration as a separate file.

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http://www.elsevier.com/artworkinstructions

You are urged to visit this site; some excerpts from the detailed information are given here.

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EPS (or PDF): Vector drawings, embed all used fonts.
TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.
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TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

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• Supply files that are too low in resolution;
• Submit graphics that are disproportionately large for the content.

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Figure captions
Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References

Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

References in a special issue
Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference style
Text: All citations in the text should refer to:
1. Single author: the author's name (without initials, unless there is ambiguity) and the year of publication;
2. Two authors: both authors' names and the year of publication;
3. Three or more authors: first author's name followed by 'et al.' and the year of publication.
Citations may be made directly (or parenthetically). Groups of references should be listed first alphabetically, then chronologically.
Examples: 'as demonstrated (Allan, 2000a, 2000b, 1999; Allan and Jones, 1999). Kramer et al. (2010) have recently shown ....'
List: References should be arranged first alphabetically and then further sorted chronologically if necessary. Abbreviated words in journal titles should be followed by a full stop. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.
Examples:
Reference to a journal publication:
Van der Geer, J., Hanraads, J.A.J., Lupton, R.A., 2010. The art of writing a scientific article. J. Sci. Commun. 163, 51–59.
Reference to a book:
Strunk Jr., W., White, E.B., 2000. The Elements of Style, fourth ed. Longman, New York.
Reference to a chapter in an edited book:
Mettam, G.R., Adams, L.B., 2009. How to prepare an electronic version of your article, in: Jones, B.S., Smith , R.Z. (Eds.), Introduction to the Electronic Age. E-Publishing Inc., New York, pp. 281–304.

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